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Proposal of a Portuguese Scale for Quality Assessment of Genetic Counselling by Counselees

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PROPOSAL OF A PORTUGUESE SCALE FOR QUALITY ASSESSMENT OF GENETIC COUNSELLING BY COUNSELEES

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AVISOS LEGAIS

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Júlia e Dinis,

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Abstract

An appropriate genetic counselling is essential when a genetic test is offered. However, to assess genetic counselling quality is a challenge for clinical genetics services worldwide due to the scarcity of effective tools to this effect. In Portugal, professionals and services have been demanding effective tools which allow evaluation of the quality of their services and consequently improving their practice and counselees care. This thesis describes the development and psychometric validation of a multidimensional scale for quality assessment of genetic counselling by the counselees. The formulation of the items and their organization were based on a Portuguese scale designed for quality assessment of genetic counselling by the healthcare professionals. After a pre-test validation, the scale was submitted to a psychometric validation using a sample of 107 counselees, 73 women and 32 men, aged 18 to 75 years old (M = 40.5; SD = 16.28), who had a genetic counselling consultation in a Portuguese clinical genetics service, between September of 2018 and May of 2019. A principal component analysis was performed to examine the scale structure. The construct validity and internal consistency were also evaluated. The results from the principal component analysis indicated good psychometric proprieties for the 'counselee's education', 'counselee's knowledge and understanding', 'counselee's individual attributes', 'relationship and communication issues', 'potential effects' and 'services provision' dimensions. Internal consistency of each dimension ranged between .70 and .90 (Cronbach's α), excepted for the dimension 'counselee's knowledge and understanding' that presented a Cronbach's alpha of. 60. As expected, all dimensions were positively and significantly correlated with each other. The results show that the scale may be a useful instrument for clinicians, services and researchers interested in monitoring the quality of genetic counselling.

***Keywords*:** genetic counselling; quality assessment tool; clinical genetics services; psychometric validation

Resumo

É essencial assegurar a oferta de um aconselhamento genético apropriado aquando da realização de um teste genético. No entanto, avaliar a qualidade do aconselhamento genético ainda é um desafio para os serviços de genética devido à escassez de ferramentas disponíveis para esse efeito. Em Portugal, profissionais e serviços têm vindo a reivindicar ferramentas efetivas que lhes permitam avaliar a qualidade dos seus serviços e, consequentemente, melhorar a sua prática, e os cuidados prestados aos consultandos. Esta dissertação descreve o processo de desenvolvimento e validação de uma escala multidimensional para a avaliação da qualidade do aconselhamento genético pelos consultandos. A formulação dos itens e a sua organização foram baseadas na escala portuguesa para avaliação da qualidade do aconselhamento genético pelos profissionais de saúde. Depois de um pré-teste, a escala foi submetida a validação psicométrica utilizando uma amostra de 107 consultandos, 73 mulheres e 32 homens, com idades compreendidas entre os 18 e os 75 anos (M = 40.5; DP = 16.28), que tiveram uma consulta de aconselhamento genético num serviço de genética nacional, entre os meses de setembro de 2018 e maio de 2019. Foi realizada uma análise de componentes principais para examinar a estrutura da escala. A validade de construto e a consistência interna foram também avaliadas. Os resultados da análise de componentes principais indicam que as dimensões 'educação', 'compreensão', 'características do consultando', 'relação profissional-consultando', 'efeitos do processo' e 'prestação de serviços' apresentam uma estrutura consistente. A consistência interna de cada dimensão variou entre .70 e .90 (α de Cronbach), com exceção da dimensão 'compreensão' que apresentou um alfa de Cronbach de .60. Como esperado, todas as dimensões apresentaram correlações positivas e significativas entre si. Os resultados indicam que a escala pode ser um instrumento útil para profissionais de saúde, serviços e investigadores interessados em monitorizar a qualidade do aconselhamento genético.

***Palavras-chave*:** aconselhamento genético; instrumento de avaliação da qualidade; serviços de genética; validação psicométrica

Résumé

Assurer l'offre d'un conseil génétique approprié est essentiel lors de la validation d'un test génétique. Toutefois, évaluer la qualité d'un conseil génétique est encore un défi pour les services de génétique car il y a peu d'outils disponibles pour l'effectuer. Au Portugal, les professionnels et les services continuent à réclamer des outils capables d'évaluer la qualité de leur service, donc d'améliorer leur pratique ainsi que les soins fournis à ceux qui sont consultés. Cette dissertation décrit le processus du développement et la validation psychométrique d'une échelle multidimensionnelle pour permettre l'évaluation de la qualité du conseil génétique, par ceux qui sont consultés. L´élaboration des questions et leur organisation ont été conçues à partir d'une échelle portugaise pour évaluer la qualité du conseil génétique des professionnels de santé. Après un pré–test, l'échelle a été soumise à la validation psychométrique pour un échantillon de 107 personnes qui ont été consultées, 73 femmes et 32 hommes, âgées entre 18 et 75 ans (M = 40.5; S =16.28), qui ont eu un rendez-vous d'avis génétique dans un service de génétique national, entre les mois de septembre 2018 et mai 2019. On a fait une analyse des composants principaux pour observer la structure de l'échelle. La validité de la construction et la consistance interne ont été aussi évaluées. Les résultats de l'analyse des composants principaux indiquent que les dimensions 'éducation', 'compréhension', 'caractéristiques de ceux qui sont consultés', 'relation professionnel-consulté', 'effets du processus' et 'prestation de services' présentent une structure consistante. La consistance interne de chaque dimension a varié entre .70 e .90 (α de Cronbach), à l'exception de la dimension 'compréhension' qui a présenté un alpha de .60. Comme prévu, toutes les dimensions présentent des corrélations positives et significatives entre elles. Les résultats indiquent que l'échelle peut être un instrument utile pour les professionnels de santé, services et rechercheurs qui s'intéressent à l'évaluation du conseil génétique.

Mots-clés: conseil génétique; instrument d'évaluation de la qualité; services de génétique; validation psychométrique

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List of Abbreviations

CGPP	Centro de Genética Preditiva e Preventiva do Instituto de Biologia Molecular e Celular – Instituto de Inovação e Investigação em Saúde da Universidade do Porto
CGS	Clinical Genetics Services
e.g.	Exempli Gratia, For Example
et al.	Et alii, and Others
FPCEUP	Faculdade de Psicologia e de Ciências da Educação da Universidade do Porto
GC	Genetic Counselling
KMO	Kaiser-Meyer-Olkin
M	Mean
PCA	Principal Component Analysis
PST	Pre-Symptomatic Test
REM	Reciprocal-Engagement Model of Genetic Counselling Practice
SD	Standard Deviation

Introduction

Due to the completion of the sequencing of the Human Genome and the huge development in genetic testing technologies, the field of genetics has grown rapidly (Ormond et al., 2018). The greater application of genetics knowledge and technologies in medicine has increased both interest in and concern about the impact of genetics information on the life of individuals and families at-risk or affected by a genetic condition (Rantanen et al., 2008) because many of these diseases have no treatment or cure (Wang, Gonzalez, & Merajver, 2004). For this reason, genetic counselling (GC) has been evolving and acquiring greater importance in genetics healthcare over the last decades (Ormond et al., 2018). In spite of its evolution and increasing importance, the evaluation of its quality remains a challenge for clinical genetics services (CGS) worldwide given the absence of effective tools available to this effect (Payne et al., 2008). In the national literature, this lack of tools is pointed out as a constraint to the affirmation of GC in Portugal (Paneque, Mendes, Saraiva, & Sequeiros, 2015b). Due to this demand, a Portuguese tool for quality assessment of GC by healthcare professionals was recently developed (Costa, 2017; Paneque et al., 2018). However, when evaluating the quality of GC, it is also important to include the perspective of the counselees because they are the real beneficiaries of the GC. Additionally, only the evaluation of both professionals' and counselees' perspectives will allow a comprehensive evaluation of GC quality. Therefore the main purposes of the present thesis are to develop and validate a scale for counselees' evaluation of GC quality.

This thesis is organized in five chapters. In the first chapter, a review of the literature about the quality evaluation of GC and in particular the counselees' perspective of GC will be presented. In the second chapter, the empirical study will be explained in detail. In the third chapter, the results will be described. In the fourth chapter, the results will be discussed and the study's theoretical and practical implications and recommendations for future studies will be addressed. Finally, in the last chapter, a summary of the main conclusions and implications of the study will be presented.

I. Theoretical Framework

1.1. Genetic Counselling

GC is a relatively recent (≈45 years) interdisciplinary field that aims to address the needs of both people and families affected by or at risk for a genetic condition (Ormond et al., 2018; Paneque, Sequeiros, & Skirton, 2012; Redlinger-Grosse et al., 2016).

The term GC was coined in 1947 by Dr. Sheldon C. Reed (McCarthy Veach, Bartels, & LeRoy, 2003). Over the years, the definition of GC has been changed as a consequence of the evolution of the field and changes in its goals (Resta, 2006). One of the most often cited definitions of GC is Fraser's (1974), in which GC is conceptualized as:

> A communication process which deals with the human problems associated with the occurrence, or risk of occurrence, of a genetic disorder in a family. This process involves an attempt by one or more appropriately trained person to help the individual or the family to comprehend the medical facts, including the diagnosis, the probable course of the disorder and available management, to appreciate the way heredity contributes to the disorder and the risk of recurrence in specified relatives, to understand the options for dealing with the risk of recurrence, to choose the course of action which seems appropriate to them in view of their risk and their family goals and act in accordance with that decision, and to make the best possible adjustment to the disorder in an affected family member and to the risk of recurrence of that disorder. (p. 637)

As this definition underlines, in a GC process, the counsellor presents medical and genetics information about the condition to the counselees, explaining its possible consequences, the probability of developing the disease or transmitting it to their offspring, and what can be done to prevent or ameliorate the condition (Pilnick & Dingwall, 2001). In Baty's words "genetic counsellors help families learn from the past, adjust to the present, and predict the future" (2018, p. 59). The counsellor also attempts to aid counselees to give meaning to the information received and to decide the course of action that seems more appropriate to them in relation to the genetics disease that affects the family (Pilnick & Dingwall, 2001). This psychosocial component of GC is greatly emphasized by some authors, such as Austin, Semaka and Hadjipavlou (2014) and McCarthy Veach, Bartels and LeRoy (2003) who define GC as an interdisciplinary area of clinical healthcare in which knowledge of genetics and counselling skills are combined to support people to cope better with medical information and psychosocial aspects of genetics diseases or the at-risk status (Baty, 2018).

Since its early years, GC has expanded and evolved steadily due to the advancement in genetic testing technology (e.g., whole genomic sequencing or the development of new genetic tests), the increasing genetics knowledge about disease etiology, the progressive integration of genetics into primary care settings, and the incremental population demand for genetics disease prevention, treatment and monitoring (Chou et al., 2018; Payne et al., 2008; Redlinger-Grosse et al., 2016; Ormond et al., 2018). With the proliferation of genetic tests for more medical conditions, GC has become an important component of healthcare across diverse sub-specialties of medicine, such as obstetrics, paediatrics, neurology, endocrinology, haematology, cardiology and oncology. This growth has led to a greater professionalization of the field, an increase of genetic counsellors around the world, as well as to greater recognition of GC by the general population (Baty, 2018; Ormond et al., 2018). However, this development is not occurring at the same pace in all countries, due to the constraints related to the functioning of healthcare systems, legal restrictions, and social or cultural norms (Ormond et al., 2018).

1.1.1. The Development of Genetic Counselling in Portugal.

In Portugal, GC arose in the nineties with the implementation of the first national programme for pre-symptomatic testing (PST) (Paneque et al., 2015b). Since then, GC has been regulated by the Portuguese law 12/2005 which establishes that a genetic test (e.g., prenatal, pre-symptomatic, predictive, susceptibility) can only be carried out after a GC consultation and written informed consent. The same law also determines that all citizens have the right to receive GC before and after a genetic test. Later, in 2009 the first Portuguese professional master's program in GC was set up at the Institute of Biomedical Sciences Abel Salazar (University of Porto). Despite these historical achievements, GC and the profession of genetic counsellor remain without full professional recognition in Portugal[1]. The number of professionals working in the field is still insufficient, and there are gaps in the professionals' training (Paneque et al., 2015b; Paneque, Mendes, Guimarães, Sequeiros, & Skirton, 2015a). According to Paneque and colleagues (2015b) factors such as the heterogeneity of standards of practice, the poor coordination between

[1]Given that the profession of genetic counsellor is not still recognized in Portugal. The term professional will be used to refer who is providing the genetic counselling consultation.

national teams, the scarcity of human resources, the educational and training needs and the absence of effective tools for professionals to assess the quality of their services are constraining the development and the full implementation of the GC in Portugal (Paneque et al., 2015b).

1.2. The Evaluation of Genetic Counselling Quality

With the increasing importance of genetics in healthcare, it has become essential to ensure that the GC professionals and services are meeting the counselee's needs and that they are providing appropriate care (DeMarco, Peshkin, Mars, & Tercyak, 2004; Wang et al., 2004; Rantanen et al., 2008). The constant monitoring and improvement of GC quality are therefore priorities for professionals and clinical genetics services (CGS)[2] because both are critical for the advancement of GC as an independent and recognized profession (DeMarco et al., 2004; Paneque et al., 2015b).

The quality assessment of GC practice is not a new theme or a new concern in the field. In the nineties, Lea (1996) defined the quality of GC as "a range of desirable outcomes of patient encounters and encompasses effectiveness, efficiency, adequacy, and acceptability" (p. 125). Since Lea's work, an effort has been made by clinical genetics professionals and CGS to develop routines and tools to assess the quality of their services (McAllister, Wood, Dunn, Shiloh, & Todd, 2011b). However, the rigorous assessment of the quality of GC remains a challenge for professionals and services worldwide (Guimarães, Sequeiros, Skirton, & Paneque, 2013; McAllister et al., 2011b; Paneque et al., 2012; Paneque et al., 2015b). As a consequence, globally, the quality evaluation in the field of GC is behind other areas of healthcare (Chou et al., 2018). This context, together with the absence of effective tools reported in Portugal and the studies' limitations discussed below, were the main reasons for aiming to develop and validate a scale for GC quality assessment by counselees in the present research.

Quality evaluation is still a neglected topic in the field, although some authors support its key role in the GC development and affirmation (Paneque et al., 2015b).

[2] Defined here as health services that offer genetic consultations, genetic counselling and genetic testing/screening (Wang et al., 2004).

Among the scarce studies focusing on these constructs, those centered on oncogenetic context are probably the most prevalent. In addition to the paucity of research on quality evaluation, the existing studies seem to have some methodological limitations (Guimarães, et al., 2013; Paneque et al., 2012; Rantanen et al., 2008). First, there is a lack of consistency regarding the conception of GC nature, goals and foci (process vs effects) adopted across studies. Some studies advance inclusively with effect criteria without previously specifying the definition and the goals of GC, and/or without a proper theoretical framework (Paneque et al., 2012). Secondly, almost all studies use cross-sectional designs, self-report instruments and small and not representative samples (i.e., participants are from self-selected populations, usually caucasian and from higher socioeconomic levels) (McCarthy Veach, Bartels, & LeRoy, 2007).

1.2.1. How to Evaluate Genetic Counselling Quality?.

Few studies examined how to evaluate the quality of GC (Guimarães et al., 2013; Paneque et al. 2012; Rantanen et al. 2008). However, it is possible to distinguish two major approaches: (a) to assess the GC as a process, and (b) to evaluate solely its potential effects or outcomes (Guimarães et al., 2013; McCarthy Veach et al., 2007).

The first approach is focused on aspects, such as how information is provided, time given to counselee to talk about their concerns and needs, and quality of the professional-counselee relationship (Bernhardt, Biesecker, & Mastromarino, 2000; Guimarães et al., 2013; McAllister et al., 2008b). The importance of the process aspects have been claimed by some authors, such as Paneque and colleagues (2015b), Pilnick (2002) and Rantanen and colleagues (2008), but few studies examined their contribution to the effects or outcomes (Chou et al., 2018; Rantanen et al., 2008; Pithara, 2014).

The second approach, in contrast, is more concerned with aspects, such as changes in reproductive behaviour, counselee's knowledge about the disease, satisfaction, perceived risk, and perceived control (Madlensky et al., 2017; McAllister et al., 2008b; McAllister, Dunn, & Todd, 2011a; Redlinger-Grosse et al., 2016; Payne et al., 2007). Despite the widespread adoption of this approach, there is still no consensual set of desirable effects or outcomes that should be applied to the evaluation of the GC quality (Chou et al., 2018; McAllister et al., 2011a).

1.2.2. Genetic Counselling Quality Indicators.

Although there is still no consensual and standard set of indicators for the quality assessment of GC (Payne et al., 2008), some proposals have already been advanced.

The EuroGentest (as cited in Guimarães et al., 2013) have produced a web-based checklist to assess logistics of genetics services consisting of eleven quality indicators of the GC practice: (a) size of and collaboration in the unit, (b) staff education, (c) physical environment and access, (d) waiting times, (e) prerequisite of counselling, (f) language, culture and communication, (g) decision-making process and consent, (h) counselee experience, (i) extended support, (j) post-consultation measures, and guidelines.

More recently, Chou and colleagues (2018) have developed a set of comprehensive quality metrics to inform quality improvement efforts in state genetics service delivery formed by the following sixteen quality indicators: (a) availability of and support for preconception services (e.g., folic acid education); (b) information referral and coordination (e.g., referral of families to support groups); (c) quality improvement (e.g., adherence to licensing requirements, published guidelines, standards, and regulations); (d) early screening and diagnosis (e.g., offer prenatal tests such as maternal serum α-fetoprotein and associate marker screening); (e) family or individual feedback (e.g., collects feedback from individuals and families concerning genetics services); (f) state provision of access to genetics services (e.g., provides access or has mechanisms in place to facilitate access to genetics services such as estate funds); (g) access to genetics professionals (e.g., the state employs or give access to specialized professionals); (h) accessibility/availability to genetics services (e.g., to establish a maximum time to a medical appointment); (i) genetics medical records (e.g., informed consent for visit is maintained as a part of the permanent medical record); (j) patient ratings of physician–patient interaction (e.g., the professional listened carefully); (l) security of electronic information (e.g., the service has a plan about security and computer access); (m) documentation of data sources (e.g., the state uses certain data sources as population-based cancer/tumor registry); (n) data linkages (e.g., the state has or has access to information systems or databases as the birth defect registry); (o) components of newborn screening program (e.g., the state has a standardized newborn's screening program formed by different components); (p) state staffing (e.g., the state has a designated genetics

coordinator); and (q) workforce training adequacy (e.g., the state implements strategies to meet the staff needs).

Overall, given that both sets of quality indicators are mainly focused on logistical and/or services provision factors, there is a clear need for a comprehensive set of quality indicators that includes other core components of GC, such as consultation contents, professional-counselee relationship and potential effects of the GC process for the counselee (Paneque et al., 2012).

1.2.3. Measures of Genetic Counselling Quality.

The tools used for quality assessment seem to be insufficient, and/or poorly disseminated amongst the professional community (Payne et al., 2008). The majority of the available tools are mainly focused on specific effects or outcomes, such as satisfaction with GC (e..g., DeMarco et al., 2004), knowledge (e.g., Erblich et al., 2005), decision-making (e.g., Michie, Dormandy, & Marteau, 2002), perceived control (e.g., Berkenstadt, Shiloh, Barkay, Katznelson, & Goldman, 1999), familial communication (e.g., Mesters et al., 1997). Or they are intended to audit the CGS focusing only in factors related to the services provision (e.g., Skirton, Parsons, & Ewings, 2005) (see Appendix A for a complete description of the main tools). Of interest to the present study, none of the existent measures seem able to evaluate all the specific aspects which may contribute to the quality of GC (Chou et al., 2018; Paneque et al., 2018; Payne et al., 2008; Redlinger-Grosse et al., 2016).

1.2.4. The Evaluation of Genetic Counselling Quality in Portugal.

The difficulties in defining indicators and the best way for measurement of GC quality are also felt in Portugal. According to Paneque and colleagues (2015a), there is a general lack of knowledge and reflection about quality indicators, as well as a scarcity of tools to assess the quality of the GC, and a lack of quality assessment routines in the national genetics services. In turn, this absence of theoretical-driven and appropriate methodological tools to evaluate the quality of GC hinders an adequate audit of CGS and the continuous improvement of genetics practice and services.

In order to overcome this absence of tools to evaluate the GC quality, Paneque and colleagues (2018) recently developed a tool for professionals working in the GC field to assess the quality of their practice. However, the need for an instrument for counselee's evaluation of the quality of GC remains.

1.3. A Portuguese Tool for Genetic Counselling Quality Assessment by Professionals

The Portuguese tool for quality assessment of GC is a multidimensional scale designed for GC professionals' evaluation of the quality of their practice.

This scale has fifty items organized in five GC quality dimensions: (1) 'education'; (2) 'counselee's characteristics'; (3) 'professional-counselee relationship'; (4) 'effects of the process in the counselee'; and (5) 'services provision'.

The scale was submitted to psychometric validation with a sample of thirty health professionals working in the field who evaluated eighty-one consultations carried out at main national genetics services (Paneque et al., 2018). The results of the validation process showed that the tool has good psychometric properties (see Table 1 for a detailed description of the scale dimensions, number of items, components and percentages of total variance explained). According to the cumulative percentage of the variance of the components of each dimension, the scale has a good construct validity (Paneque et al., 2018). Moreover, the dimensions presented a good internal consistency ($.83 \leq \alpha$ of each dimension $\leq .92$).

Despite being a new tool, this pioneer scale stands out from the remaining tools because it seeks to enable a comprehensive understanding of GC quality, considering both process-effects relationship and services provision dimensions. Furthermore, it is based on Reciprocal-Engagement Model (REM), the first proper model of GC practice (Paneque et al., 2018; McCarthy Veach et al., 2007). Given its clinical usefulness, the scale was received with great interest by Portuguese professionals, and professionals from Norway, Spain, France and Australia have already manifested interest in its cross-cultural adaptation and validation (Paneque et al., 2018).

Table 1

Structure of the Portuguese tool for genetic counselling quality assessment

Dimension	Number of Items	Components	Total Variance Explained
Education	12	To ensure the comprehension	42.54%
		To provide genetics information	16.47%
		To establish a mutual agenda	10.15%
Counselee's characteristics	11	Emotional experience and motivations	59.24%
		Decision-making support	14.20%
Professional-Counselee relationship	11	Therapeutic relationship	44.46%
		Counselee's acceptance	12.60%
		Reflexive Practice	10.35%
		Professionalism	9.36%
Effects of the process in the counselee	9	Empowerment	59.50%
Services provision	8	Services organization	54.32%
		Preparation of the counselee to the consultation	16.74%

Note. Adapted from "Proposta de uma escala portuguesa para a avaliação da qualidade do aconselhamento genético: Uma nova ferramenta para os profissionais da saúde by M. Paneque, C. Costa, C. Lemos, M. Alves Ferreira, J. Sequeiros and M.S. Lemos, 2018, *Acta Médica Portuguesa*, p. 325.

1.4. The Counselee's Perspectives of Genetic Counselling

To develop a tool for counselee evaluation of the quality of GC it is essential to understand how counselees perceive the GC and CGS, namely what are the aspects that they consider most important and beneficial because these aspects may constitute potential

quality indicators of GC (Payne et al., 2008). A brief literature review[3] of the main counselee's perceptions and views about GC and CGS was then performed. The major aspects identified were organized in clusters (see Table 2).

Table 2

Counselee's views and perceptions of genetic counselling and clinical genetics services

Genetic Counselling	Clinical Genetics Services
Quality of the professional-counselee relationship	Practical and logistical aspects
Process factors	Tailored family care
Professional's characteristics and skills	Openness to establishing long-term relationships
Perceived effects or outcomes	

Within the field of counselee's perspectives of GC, the quality of the professional-counselee relationship is perhaps the most cited aspect (Bernhardt et al., 2000; Guimarães et al., 2013; Macleod, Craufurd, & Booth, 2002; McAllister et al., 2008a, 2008b; Skirton, 2001). The counselees seem to value the establishment of a positive and empathic interpersonal relationship with the professional (McAllister et al., 2008a, 2008b). Counselees' perceptions about the quality of the relationship appears to be related to some professionals' skills, such as compassion, empathy, responsiveness, attentiveness, flexibility, engagement, confidence, sensitivity and supportiveness (McCarthy Veach, Truesdell, LeRoy & Bartels, 1999).

Some factors related to the GC process are also mentioned by counselees (Bernhardt et al., 2000; MacLeod et al., 2002; McAllister et al., 2008a, 2008b). Among them, two deserve special mention given their frequency: the time spent with the professional and how information is provided (McAllister et al., 2008a). Feeling they have time to talk about their doubts and concerns without hurries or pressures is important for the counselees. Being offered information in an accessible and lay language, without medical jargons, and adjusted to their previous knowledge is also relevant for counselees. Regarding the practice model adopted by the professional, the counselees seem to

[3]Studies developed on oncogenetic context were not included given the proper specificities of this context and the unique needs of this group of counselees.

appreciate a non-directive and patient-centred stance (Bernhardt et al., 2000; Costal Tirado et al., 2017; Paneque et al., 2015a; Skirton, 2001).

The professional's characteristics and skills are equally considered relevant by counselees (Bernhardt et al., 2000; Davey, Rostant, Harrop, Goldblatt, & O'Leary, 2005; MacLeod et al., 2002; McAllister et al., 2008a, 2008b; Paneque et al., 2015b). Some professional's skills valued by counselees include the ability to listen, the capacity to empathize, social competence, ability to explore and address doubts and emotions, communication skills, open attitude, and the ability to answer the counselee's questions (McCarthy Veach et al., 1999). Another aspect very frequently mentioned by counselees is the perception of the professional as an expert or as a reliable source of knowledge. This seems to be a very important aspect to counselees because it contributes to the feeling of being understood and to the feeling that their problem has been validated by an expert, which is reassuring for counselees (MacLeod et al., 2002; McAllister et al., 2008a).

The aspects related to the perceived benefits of GC are also mentioned by counselees. Among the perceived benefits it is possible to highlight a better family communication of genetics information, the enhancement of understanding about the genetic condition, the greater facility in decision-making about the genetic condition, the relief of uncertainty and feelings of vulnerability, the decrease of anxiety about the genetic family condition, and the recovery of some confidence and control over their lives (Bernhardt et al., 2000; Guimarães et al., 2013; McAllister et al., 2008a, 2008b; McAllister et al., 2011b; McCarthy Veach et al., 1999; Pithara, 2014).

In relation to counselee's perceptions and views about CGS, three aspects are usually mentioned in the literature: (a) practical and logistical issues, (b) tailored family care and (c) openness to establish long-term relationships. Regarding the practical and logistical issues, it is important to counselees that the services are local, accessible and have open access. The duration of consultations is also relevant, as well as the proximity and privacy of the service, the kindness and availability of the administrative staff, the physical environment, the reduced waiting time for the consultation, the multidisciplinary approach, and the number of the available consultations (Bernhardt et al., 2000; Guimarães et al., 2013; McAllister et al., 2008b; Paneque et al., 2012).

Tailored family care is another aspect perceived as relevant by counselees. This aspect is related to the fact that in some services the GC is offered not only to the counselees but also to other members of their families (MacLeod et al., 2002). This

availability gives to the family the opportunity to make informed decisions about their family life, to clarify the risk to the wider family, and to improve their communication about the genetic disease (McAllister et al., 2008a), therefore contributing to improve counselees hope for their own future and for their offspring future (McAllister et al., 2008a).

The openness to establishing long-term relationships across the follow-up consultations is another aspect valued by counselees. This issue is important to counselees because diverse doubts and questions can emerge at different life stages and for different family members so it is useful to have access to the service over time (McAllister et al., 2008a; Pithara, 2014). Besides that, this openness allows the establishment of an ongoing supportive relationship with the professional (Bernhardt et al., 2000), which is also appreciated by the counselees.

In general, these aspects seem to be equally pertinent to the Portuguese counselees. A study of Guimarães and colleagues (2013) indicated that the counselees appreciate aspects as a multidisciplinary approach, the availability of resources, and the provision of information, particularly when this information is adapted to their previous knowledge, or when it is provided in a more clear way, facilitating their understanding of that which they have already read or heard. Concerning the provision of information, the counselees also considered the previous assessment of their prior lay beliefs about the disease and the consultation important because that may affect their comprehension of the information. Moreover, the counselees have highlighted as important the establishment of a good professional-counselee relationship, as well as the adoption of an emphatic and open stance by the professional. Counselling skills such as empathy and emotional engagement are also mentioned as essential for an effective GC (Guimarães et al., 2013).

1.5. Reciprocal-Engagement Model of Genetic Counselling Practice as Theoretical-Practical Underpinning

It is essential to adopt a theoretical framework, based on clinical practice, which defines goals, essential process components, and desired effects or outcomes for GC (Wang et al., 2004) to develop an effective tool for GC quality evaluation by the counselees, because the quality of GC is deeply related to the extent that the defined goals

are attained, the essential process components are present during the consultation and the desired effects are reached and perceived by counselees (Lea, 1996).

The Reciprocal-Engagement Model (REM) is the first proper model of the practice of GC. This model was developed with the goal of offering to the professionals working in the field a comprehensive practice model, capable of providing practice guidelines and quality standards for the evaluation of GC and CGS (McCarthy Veach et al., 2007).

In its first years, GC practice was guided by models of practice from medicine, education and psychology, such as Carl Roger's Client-Centered Counselling (McCarthy Veach et al., 2003). However, with the GC evolution, a need for a new model proper to GC practice has increased. Due to this demand, McCarthy Veach and colleagues (2007) organized a conference with the program directors of Masters in GC to develop a first proper model of the practice of GC – the Reciprocal-Engagement Model (REM) – based on the current clinical practices. According to the authors, the term 'reciprocity' emphasizes that the models' components are not discrete, rather "they reciprocally affect each other, and each is necessary but not sufficient individually for influencing genetic counselling outcomes" (p.726). The term 'engagement' highlights that both professional and counselee have participation in this process. Together, these two words are intended to describe "a mutual process in which the genetic counsellor and patient participate in an educational exchange of genetic and biomedical information shaped by their unique psychosocial identities" (p. 726).

REM is based on the current practice of GC and is formed of five tenets, seventeen goals, thirty-eight strategies and fourteen behaviours, which can be summarized in three major dimensions – education, individual attributes and relationship. The first dimension embodies the first tenet and associated goals, strategies and behaviours. The second dimension represents the third, the fourth and the fifth tenet of the model and their respective goals, strategies and behaviours. The last dimension represents the second tenet and "is at the center of the model" (McCarthy Veach et al., 2007, p. 721) because as McCarthy Veach and colleagues emphasize "the relationship serves as the conduit, providing an alliance in which the patient feels supported, cared about, connected, and validated" (p.725).

The first component of REM - tenets - is associated with doctrine, and generalized beliefs about profession and professional responsibilities (McCarthy Veach et al., 2007). The five, "mutually influential" (Redlinger-Grosse et al., 2016), tenets of this model are:

(1) “genetics information is key”; (2) “relationship is integral to genetic counselling”; (3) “counselees autonomy must be supported”; (4) “counselees are resilient”; and (5) “counselees emotions make a difference” (p. 241). The second component - goals - is divided into two categories - process goals and outcome goals. Process goals are fundamentally the responsibility of the professionals and are concerned with “the conditions that must be present during genetic counselling sessions in order to achieve desired genetic counselling outcomes” (e.g., “genetic counsellor and patient establish a bond”) (McCarthy Veach et al., 2007, p. 719). Outcome goals are concerned with the desired outcomes in the GC and are co-constructed by the professional and the counselee that share responsibilities in their attainment (e.g., “patient self-esteem is maintained or increased”) (McCarthy Veach et al., 2007, p.721). The third component - strategies - is concerned with the plan or method elected by the professional in achieving those goals (e.g., “active listening”, McCarthy Veach et al., 2007, p.720). The fourth component - behaviour - is the more explicit component and it is concerned with professional actions (e.g., “ask questions about patient coping skills”, McCarthy Veach et al., 2007, p.720).

The first tenet emphasizes the importance of the provision and discussion of genetics information to the counselees. For this model, the counselees want to receive information when they seek a GC service and this is one of the most unique aspects of GC (McCarthy Veach et al., 2007). This tenet embraces four goals, seven strategies and six behaviours (see Appendix B for a complete description).

The second tenet is based on the belief that a strong professional-counselee alliance is fundamental to address counselee’s concerns. For this model, the GC is a “relationally based helping activity” whose outcomes are dependent on the quality of the professional-counselee relationship (McCarthy Veach et al., 2007, p.721). The professional-counselee relationship is as important as providing genetics information to the GC outcomes (McCarthy Veach et al., 2007). This tenet is associated with three goals, seven strategies and eight behaviours (see Appendix B for a complete description).

The third tenet lies in the belief that counselees know best what is better for them and therefore they can make their own decisions (McCarthy Veach et al., 2007). This is formed by four goals, ten strategies and four behaviours.

The fourth tenet is in some way related to the last one because this presumes that the typical counselee has the strength and personal capabilities needed to deal with a GC

process. This tenet embraces three goals, nine strategies and one behaviour (see Appendix B for a complete description).

The last tenet recognizes the relevance of the counselee's emotions within the GC process. For the model, counselee's emotions interact with and affect all GC processes and outcomes, for example, counselee' emotions will influence his comprehension of information (McCarthy Veach et al., 2007). This tenet is compounded by three goals and five strategies.

Recently, some studies have presented new evidence about the model further confirming its validity "(e.g., Hartmann, McCarthy Veach, MacFarlane & LeRoy, 2015; Redlinger-Grosse et al., 2016; Paneque et al., 2018). Hartmann and colleagues (2015) have shown that the goals of the model are recognized as useful and important by genetic counsellors. Redlinger-Grosse and colleagues (2016) have used the REM as a guiding framework to identify a preliminary comprehensive list of GC outcomes that can be used in the future for evaluating the efficiency of the GC services and/or for linking specific outcomes with specific aspects of GC process (Redlinger-Grosse et al., 2016). Schmidlen and colleagues (2018) have applied the REM to the emerging genomic counselling context developing a framework of counselling components and strategies, based on tenets of REM, for the delivery of genomic results. As aforementioned, Paneque and colleagues (2018) have used REM as a theoretical and practical framework to develop a scale to measure the quality of GC.

1.6. Study Purpose and Aims

This study is part of a wider project developed in collaboration between the FPCEUP and the Centro de Genética Preditiva e Preventiva (CGPP) aimed at building a novel comprehensive system for assessing the quality of GC.

In the first stage of this project, the scale for professionals' evaluation of the quality of their practice was developed and validated (Costa, 2017; Paneque et al., 2018).

Here, the main purposes were to develop and validate an analogous tool designed for GC quality assessment by counselees. Specific aims of this study were (a) to develop the scale, (b) to pre-test the scale and (c) to examine its structure and (d) to evaluate its psychometric properties.

This study intends to contribute to the existent research on evaluation of GC, in general, and counselees' evaluation of GC quality, in particular, by providing the first scale theoretically and methodologically sound to the GC quality evaluation by the counselees.

II. Methods

2.1. Scale Development

The scale development was mainly based on the previously developed scale for professionals to assess the quality of GC (Paneque et al., 2018). The main findings of the literature review about counselee's perspectives of the GC were also used to develop the scale dimensions and items, aiming to improve the scope of the scale and enhance its content validity. Integrating the literature review with the professionals scale items' content and wording, and structure, a first draft of the present scale with fifty-two items was developed.

The scale was conceptualized as containing five different dimensions. The professional scale items' assessing reflexive practice and professionalism were not included in the present scale. Based on the literature review, five new items were added to this scale. Item 3.9. that is concerned with the counselee's evaluation of the professional perceived expertise. Item 4.5. that is related to effect of GC on the improvement of family communication of genetics information. Item 4.8. that is concerned with the extent to which the counselee's expectations were met. Item 5.9. that aims to evaluate whether tailored family care was provided by clinical genetics services. Item 5.10. that assesses the clinical genetics services openness to establish long-term relationships. The addition of these items to the scale was supported by the fact of these items could be harmoniously integrated into the scale structure without compromising its internal coherence.

The majority of the items were worded in a positive direction, with the exception of the items 3.4., 3.5. and 3.6.. Negatively phrased items were avoided, as well as biased, leading and/or double-barreled items (Leavy, 2017). The items wording and content were verified by three different researchers that examined their adequacy, compared the two scales and made suggestions to increase their appropriateness and comparability. One of the researchers has a large clinical experience in the field of GC and another is an expert in questionnaire design.

A five-point Likert-type response scale was used ranging from 1 (strongly disagree) to 5 (strongly agree) (3 = agree), with higher scores indicating higher levels of perceived quality. An additional option - "not applicable" - was added to the scale given that some items may not apply to certain GC types of consultation due to its nature or to the specific

clinical setting where the consultation took place. For example, in a consultation to communicate the genetic test result the professional would not be expected to ask questions related to counselee personal or familial background because this is usually content of the previous consultations.

Paper-and-pencil version and an online version of the scale were created to facilitate the data collection.

2.2. Pre-testing: Face and Content Validity of the Scale

A pre-testing is an important step in the process of developing a new scale because it enables the analysis of the suitability and the wording of the items, as well as, the scale face validity and its ability to gauge the construct under investigation (Leavy, 2017).

For pre-testing the scale, firstly, one of the researchers who participated in the professionals' scale development was interviewed for feedback and his/her suggestions incorporated.

Secondly, a sample of adults who had had a GC consultation between June and August of 2018 were recruited from CGPP. The recruitment of the pre-test sample was mediated by a professional working at CGPP. Given the reduced number of counselees available in this service during that period, all adults who had a GC consultation at CGPP in those months were invited to collaborate in the scale's pretesting. They also received a participation information sheet about the study and written informed consent and were informed that the main aim of their participation was to evaluate the quality of the scale rather than to assess the performance of the professional or the consultation quality. Seven counselees, 4 men and 3 women, with ages ranging from 18 to 68 (M = 32.71, SD = 20.51) agreed to answer the scale. A cognitive interview was then conducted with 5 of those participants.

The more common application of cognitive interview, which consists of the administration of the draft scale followed by the collection of verbal reports about the understanding of the scale items and response scale, was used (Beatty & Willis, 2007). The verbal material was elicited through a flexible semi-structured interview protocol created to the effect and based on the verbal probing method (Willis, 2015) (see Appendix C for a detailed description of the cognitive probes used). This method was chosen for being less burdening to the participants, interfering less on the answer process and being capable of

eliciting information stored in short-term memory (Beatty & Willis, 2007; Willis, 2015). With regard to the timing of the probe, a hybrid approach proposed by Willis (2015) was adopted, which consisted of a retrospective probing after each dimension of the scale.

Cognitive interviews were conducted face to face at CGPP. The interviews duration ranged between fifteen and thirty minutes. Participants answered some verbal probes to explore whether items were understood as expected and to test their relevance and ambiguity. During and after the interviews, the interviewer took written notes about the participants' verbatim. The notes were analyzed following the guidelines suggested by Willis (2015).

As a result of the cognitive interviewing analysis, six items were re-worded to increase their clarity and ease their understanding (see Appendix D for a detailed description of the modifications in the items). The decision to re-word some items was discussed with the two experts above mentioned until consensus was reached. The scale graphic design was also modified in order to improve its visual appearance and clarify the correct usage of the response option – 'not applicable'. In addition, an example was added to the scale instructions aiming to enhance the comprehension of that response option meaning.

2.3. Scale Description

The scale validation version comprised fifty-two items organized into five conceptual dimensions that generally corresponded to those in the instrument for quality assessment by professionals (Costa, 2017; Paneque et al., 2018): (a) 'genetic education'; (b) 'counselee's individual attributes'; (c) 'relationship and communication issues'; (d) 'potential effects'; and (e) 'services provision'.

The 'genetic education' dimension had twelve items (from 1.1. to 1.12) (e.g., "O profissional forneceu-me informações sobre os testes genéticos, como por exemplo: os procedimentos, os possíveis resultados e limitações"). The 'counselee's individual attributes' comprised eleven items (from 2.1. to 2.11.) (e.g., "O profissional perguntou-me e compreendeu o(s) motivo(s) do meu pedido de consulta). The 'relationship and communication issues' dimension included nine items (from 3.1. to 3.9.) (e.g., "O profissional não emitiu juízos de valor relativamente aos meus pontos de vista"). The

'potential effects' dimension comprised ten items (from 4.1. to 4.10.) (e.g., "Sinto-me mais capacitado para comunicar com os meus familiares acerca desta doença e/ou o seu risco"). The 'services provision' dimension had ten items (from 5.1. to 5.10.) (e.g., "A duração da consulta foi adequada").

The scale comprised also three sociodemographic questions (age, gender and clinical setting of the GC consultation).

The average time needed to answer the scale ranged between five to ten minutes.

2.4. Procedure

After approval from FPCEUP Ethics Committee was obtained, all main national genetics services[4] were invited to take part in this study through the management of the participants' recruitment process.

An email was sent to each director of national CGS and/or other professionals working in the services, inviting them to participate and describing the study context, goals, methodology and means of dissemination of the results. The email, for ethical purposes, also requested the nomination of a professional per service responsible for the study to ensure the anonymity of both the professionals and counselees. The eligibility criteria (had had a GC consultation, older than eighteen years, able to speak and read in Portuguese and provide their written informed consent) and exclusion criteria (having a cognitive disorder affecting consent ability) were indicated. As well as the participation options: (a) answer the online version through Survey Monkey (a survey software, Palo Alto, CA, USA); (b) answer at home and send the scale by postal service; and (c) answer in the service and deliver the scale to the administrative staff. Although the process of data collection has varied across the services, some general recommendations in this regard were given, namely: (a) counselees should be approached individually and after their GC consultation, and (b) should be informed that their answers would be kept confidential, (c) would not be shared with the professional who provided the consultation, and (d) at this stage would not be used for evaluating the performance of the service neither the

[4]Presently, there are seven CGS in Portugal and other ten hospital services which offer GC consultations (Costa, 2017).

professional. The contents of the scale and study objectives should be explained to the counselees as well.

A study protocol, the scale's validation version, a participant information sheet and the consent forms were attached to this email. Later, the same files were sent in paper format to the services that had answered positively to the invitation.

2.5. Ethical Considerations

The study was approved by FPCEUP Ethics Committee. All procedures performed were in accordance with the ethical standards of this institutional research committee and with the 1964 Helsinki declaration and its later amendments. Written informed consent was obtained from all participants. Participation was anonymous, confidential and voluntary, and the participants did not earn any recompense for participation. The collected answers were pseudonymised through a codification technique and the personal data (gender, age or GC consultation clinical setting) were encrypted in a database using numeric codes.

2.6. Participants

The sample of the study is formed by individuals who had a GC consultation at the following national CGS: (a) CGPP; (b) Centro Hospitalar e Universitário de Coimbra; (c) Centro Hospitalar Universitário Lisboa Norte and (d) Hospital Divino Espírito Santo (Azores), between September of 2018 and May of the current year. The sample comprises 107 participants, 73 female and 32 male (see Table 3), who were selected using the convenience sampling method, a non-probabilistic sampling process (Marôco, 2007). The age of the participants ranged from 18 to 75 (M = 40.5; SD = 16.28). In relation to the clinical setting, the following GC clinical settings were included: prenatal (n = 3), oncogenetic (n = 18), genetic diagnosis (n = 32) and predictive test (n = 54). For ethical reasons, those potential participants who were approached to participate and decided not to take part in the study were not asked to justify their choice. The number of consultations per service during this period was not obtained for ethical reasons too, so it is not possible to report accurate participation rates.

Table 3

Sample characterization

	Prenatal	Oncogenetic	Genetic Diagnosis	Predictive Test	Total
N	3 (2.8%)	18 (16.8%)	32 (29.9%)	54 (50.5%)	107
Gender					
Male	-	2 (11.1%)	13 (40.6%)	17 (31.5%)	32
Female	3 (100%)	14 (77.8%)	19 (59.4%)	37 (68.5%)	73
Age					
18-29	-	2 (11.1%)	6 (18.7%)	20 (37%)	28
30-39	2 (67%)	3 (16.67%)	11 (34.4%)	10 (18.5%)	26
40-49	1 (33%)	2 (11.1%)	11 (34.4%)	9 (16.7%)	23
50-59	-	4 (22.2%)	1 (3.1%)	3 (5.5%)	8
60-69	-	4 (22.2%)	-	7 (13%)	11
70+	-	3 (16.67%)	-	4 (7.4%)	7

Note. Presented percentages are valid percentages.

2.7. Data Analysis

All raw-data were entered into IBM Statistical Package for the Social Sciences 25.0. for analysis. Descriptive statistics (item level) was calculated to analyze possible data entry error and examine items sensitivity.

Structure of the scale was examined using principal component analysis (PCA). PCA was conducted separately for each dimension of the scale. Given this is a new instrument, eigenvalues (equal or above 1) were used as the criterion for extraction of components. Solution rotation was performed in order to simplify and clarify data structure, and increase the components interpretability (Bryman & Cramer, 2003; Field, 2013; Tabachnick & Fidell, 2012). Direct oblimin oblique rotation was used because attending to the scale's theoretical background it was expected that components would be correlated (Tabachnick & Fidell, 2012). Components retention followed Kaiser's criteria (Field, 2013). Graphical scree test was used in complement to verify the best component solution (Tabachnick & Fidell, 2012). Items selection and retention was decided based on empirical, theoretical and clinical criteria. Empirically, the following criteria were used: (a) communalities below .40, (b) component loadings below .30; and (c) items that cross-

loaded in more than one component with a difference between .10 and .15 (Field, 2013). The theoretical consistency of the components was analyzed using the REM and discussed by the group of researchers above mentioned. The items clinical relevance was also discussed by the group of researchers until consensus was reached. The clinical relevance was elected as an overweight criterion on items selection and retention because some items are fundamental quality indicators, which cannot be discarded in quality evaluation regardless of statistical results. Interpretation and naming of the components (following oblique rotation and items selection) were based primarily on the components identified in the scale for professionals (Costa, 2017; Paneque et al., 2018) and the REM of practice of GC (McCarthy Veach et al., 2007).

Prior to the PCA, some preliminary analyses were performed. Missing data analysis was performed using descriptive statistics of each item. Sample size adequacy was tested using the Kaiser-Meyer-Olkin statistic (KMO). KMO values equal to or greater than .5 were considered acceptable (Field, 2013). Bartlett's test of sphericity was used to test whether the original correlation matrix was an identity matrix (Field, 2013). Correlation matrix was observed to look for multicollinearity and singularity problems. The cut-off value of .90 was adopted to analyze the correlation values (Field, 2013).

Pearson's correlation among scale dimensions was used to assess construct validity and understand better the relationships among the dimensions. For calculating the correlations, a composite dimension mean was created for each dimension, based on the scores of items which constitute each dimension. All items were equally weighted in this mean. The strength of all correlations was evaluated based on prevailing statistical standards (Bryman & Cramer, 2003).

Reliability was assessed using an internal consistency measure - Cronbach's alpha coefficient - for each component and dimension. Cronbach's alpha values between .70 and .80 were considered acceptable. Corrected item-total correlations and Cronbach's alpha if item deleted were also calculated in order to examine the contribution of individual items to each dimension. Items with an item-total correlation equal to or higher than .3 were considered as meaningful to the dimension.

III. Results

3.1. Preliminary Analyses

There were no items with 5% or more missing data (see Appendix F for detailed results). The KMO measure of all dimensions ranged from .69 to .89, demonstrating the adequacy of the sample size for PCA. The item measures of sampling adequacy ranged between .51 and .95, further confirming the sample size adequacy. The Bartlett's test of sphericity was significant and yielded adequate values for all dimensions [$\chi^2(10) = 202.17$, $p < .001$; $\chi^2(21) = 174.13$, $p < .001$; $\chi^2(45) = 549.33$, $p < .001$; $\chi^2(28) = 481.36$, $p < .001$; $\chi^2(45) = 632.15$, $p < .001$; $\chi^2(36) = 388.52$, $p < .001$ for 'counselee's education', 'counselee's knowledge and understanding', 'counselee's individual attributes', 'relationship and communication issues', 'potential effects' and 'services provision' dimensions, respectively]. All items presented correlations below .90 (Field, 2013; Tabachnick & Fidell, 2012).

3.2. Principal Component Analysis

3.2.1. 'Genetic Education' Dimension.

Together, the set of items that were expected to assess the 'genetic education dimension' did not present sufficient statistical robustness, neither satisfactory theoretical-practical consistency. Therefore following clinical and theoretical criteria (McCarthy Veach et al., 2007), these items were reorganized into two distinct dimensions: 'counselee's education' (items 1.2., 1.3., 1.4., 1.5. and 1.12.) and 'counselee's knowledge and understanding' (items 1.1., 1.6., 1.7., 1.8., 1.9., 1.10. and 1.11.). PCA was performed for each dimension separately.

3.2.1.1. 'Counselee's Education' Dimension.

PCA for 'counselee's education' items yielded a two-component solution explaining 74.7% of the total variance (see Table 4 for detailed results).

The first component, with three items, was defined as ‘to provide biomedical information’ because the three items are related to the provision of information related to the disease and test. Example items included, “O profissional forneceu-me informações sobre a doença, como por exemplo: os sintomas, a idade e o modo de início, o prognóstico e os tratamentos possíveis” (item 1.2.). This component accounted for 54.3% of the variance, corresponding to an eigenvalue of 2.71. The component loadings ranged between .77 and .97 (M = .88).

The second component, with two items, was labelled as ‘to identify additional resources’ because both items are related to the provision of information about additional resources or sources of support such as patient associations. Example items included, “O profissional forneceu-me informações sobre possíveis fontes de apoio, como por exemplo: associações de doentes, instituições de apoio social e outras redes sociais de apoio” (item 1.5.). This component accounted for 20.4% of the variance, corresponding to an eigenvalue of 1.02. The component loadings were of .77 (1.5.) and .86 (1.6.).

The component ‘to provide biomedical information’ presented an acceptable internal consistency (Field, 2013) unlike the component ‘to identify additional resources’ which presented a lower internal consistency. Nevertheless, this component was retained given its theoretical consistency and the relevance of its items as fundamental quality indicators of GC.

Table 4

Component loadings after rotation and items selection of the ‘counselee’s education’ dimension

	Component loadings		
Items	C1	C2	h^2
1.2. Information about the disease.	**.90**		.81
1.3. Information about the genetic test.	**.97**		.89
1.4. Information about reproductive alternatives.		**.86**	.71
1.5. Information about support sources and resources (*e.g.*, patient associations).		**.77**	.65
1.12. Confidentially.	**.77**		.68
Total variance explained (%)	**54.3%**	**20.4%**	
Eigenvalue following rotation	**2.71**	**1.02**	
Cronbach’s alpha	**.86**	**.52**	
Extraction method: Principal component analysis Rotation method: Oblimin with Kaiser normalization			

Rotation converged in 4 iterations

Note. As a consequence of the existence of missing values in one or more scales, N = 105. Values were obtained from pattern matrix table. Items which were retained in the component of that column are in boldface. h^2 = Final communality estimate; C1 = Component one; C2 = Component two.

3.2.1.2. 'Counselee's Knowledge and Understanding' Dimension.

PCA for 'counselee's knowledge and understanding' items yielded a two-component solution explaining 57.3% of the total variance (see Table 5 for detailed results).

The first component, with four items, was labelled as 'meaningful understanding' because the four items which loaded on this component are related to the professional strategies to actively engage the counselee in the consultation, to facilitate the counselee meaningful understanding of information and to ensure the usefulness of the information for the counselee. Example items included, "O profissional procurou saber se a informação fornecida foi importante para mim" (item 1.9.). This component accounted for 38.2% of the variance, corresponding to an eigenvalue of 2.67. The item 1.1. presented a communality lower than the cut-off value of .40 (.12) but it was maintained due to its relevance as a fundamental quality indicator of GC. The remaining component loadings ranged between .75 and .88 (M = .82).

The second component, with three items, was defined as 'strategies to facilitate counselee's understanding' because all of its items represent strategies to facilitate counselee's understanding of the information and to assess counselee's understanding of information. Example items included, "O profissional pediu-me para resumir, pelas minhas próprias palavras, as informações que recebi" (item 1.11.). This component accounted for 19.1% of the variance, corresponding to an eigenvalue of 1.34. The item 1.6. cross-loaded on both components but it was included in this component, with which it is conceptually more related. The component loadings ranged between of .48 and .80 (M = .68).

As a consequence of the 1.1. and 1.6. items retention both components presented a lower Cronbach's alpha (.59 and .56, respectively).

Table 5

Component loadings after rotation and items selection of the 'counselee's knowledge and understanding' dimension

	Component loadings		
Items	C1	C2	h^2
1.1. Counselee's expectations.	**.34**		.12
1.6. Questions about counselee's understanding.	.51	**.48**	.58
1.7. Language clarity.	**.88**		.75
1.8. Doubts.	**.83**		.67
1.9. Information usefulness.	**.75**		.65
1.10. Audiovisual and didactic materials.		**.76**	.55
1.11. Resume information provided.		**.80**	.69
Total variance explained (%)	**38.2**	**19.1**	
Eigenvalue following rotation	**2.67**	**1.34**	
Cronbach's alpha	**.59**	**.56**	
Extraction method: Principal component analysis Rotation method: Oblimin with Kaiser normalization			
Rotation converged in 5 iterations			

Note. As a consequence of the existence of missing values in one or more scales, N = 105. Values were obtained from pattern matrix table. Items which were retained in the component of that column are in boldface. h^2 = Final communality estimate; C1 = Component one; C2 = Component two.

3.2.2. 'Counselee's Individual Attributes' Dimension.

A first PCA, the item 2.3. was eliminated because it presented a lower communality (.29) and it was not considered an indispensable quality indicator in the clinical practice (see Table 6 for detailed results).

A second PCA, without this item, resulted in two components that explained in combination 62.7% of the total variance (see Table 6 for detailed results).

The first component, with seven items, was defined as 'emotional experience, motivations and decision-making support' because some of its items are related to counselee's emotions, and other items represent motivations to pursue with the test and strategies used by professional to support the decision-making (e.g., to explore the potential life changes caused by genetic test). Example items included, "O profissional ajudou-me a refletir sobre os prós e os contras das minhas opções" (item 2.8.) and

"Durante a consulta tive espaço para exprimir as minhas emoções" (item 2.6.). This component accounted for 50.6% of the variance, corresponding to an eigenvalue of 5.06. The item 2.11. presented a lower communality (.36) but it was retained for this component given its clinical relevance. The component loadings ranged between .40 and .91 (*M* = .71).

The second component is formed of three items that together explained 12.1% of the variance, corresponding to an eigenvalue of 1.21. The retained items are all related to the adequacy of consultation to the counselee characteristics and needs, therefore the component was labelled as 'counselee-centred care'. Example items included, "A consulta foi organizada de forma a responder às minhas necessidades" (item 2.1.). The item 2.1. cross-loaded on both components, but it was retained for this factor, as it is clearly more pertinent to an expression of the adequacy of consultation to the counselee characteristics rather than emotional experience and motivations and support to the decision-making, and given its higher loading on this component (.51). The remaining component loadings were of .84 (item 2.2.) and .90 (item 2.10.).

Both components presented acceptable values of internal consistency (.85 and .75, respectively) (see Table 6).

Table 6

Component loadings after rotation and items selection of the 'counselee's individual attributes' dimension

	Component loadings		
Items	C1	C2	h^2
2.1. Consultation meeting my needs.	.39	**.51**	.58
2.2. Counselee's reason for consultation.		**.84**	.76
2.3. Values and beliefs related to genetic counselling (*e.g.*, religion).	**-**	**-**	.29
2.4. How counselees and their families cope with the disease.	**.63**		.42
2.5. Counselee's emotional reactions.	**.87**		.64
2.6. Expression of emotions during the consultation.	**.73**		.66
2.7. Life changes caused by genetic test.	**.91**		.77
2.8. Genetic test pros and cons.	**.87**		.74
2.9. Feeling secure during the consultation.	**.55**		.62
2.10. Informed consent.		**.90**	.72
2.11. Next steps after the consultation.	**.40**		.36
Total variance explained (%)	**50.6**	**12.1**	
Eigenvalue following rotation	**5.06**	**1.21**	

Cronbach's alpha	**.87**	**.75**
Extraction method: Principal component analysis Rotation method: Oblimin with Kaiser normalization		
Rotation converged in 6 iterations		

Note. As a consequence of the existence of missing values in one or more scales, N = 105. Values were obtained from pattern matrix table. Items which were retained in the component of that column are in boldface. h^2 = Final communality estimate; C1 = Component one; C2 = Component two.

3.2.3. 'Relationship and Communication Issues' Dimension.

After a first PCA, item 3.8. was eliminated because it cross-loaded on both components and it was not considered an indispensable quality indicator from a clinical perspective. Furthermore, as the item 3.2. also measures active listening, its elimination did not mean a loss of a quality indicator.

A second PCA, without item 3.8., resulted in two components that explained in combination 72.3% of the total variance (see Table 7 for detailed results).

The first component, with five items, was labelled as 'counselee-professional relationship' because all items are related to counselee's perception about how professionals interact with them. Example items included, "O profissional ouviu-me com atenção e interesse" (item 3.2.). This component accounted for 49.7% of the variance, corresponding to an eigenvalue of 3.98. The component loadings ranged between .73 and .93 (M = .81).

The second component, with three items, was defined as 'counselee's acceptance' given that all of these items are related to the professional respect by the counselee values, decisions and perspectives. Example items included, "O profissional evitou transparecer o seu próprio ponto de vista quando discutimos as minhas opções" (item 3.5.). This component accounted for 22.6% of the variance, corresponding to an eigenvalue of 1.80. The component loadings ranged between .88 and .91 (M = .89).

Both components presented acceptable values of internal consistency (.86 and .88, respectively).

Table 7

Component loadings after rotation and items selection of the 'relationship and communication issues' dimension

	Component loadings		
Items	C1	C2	h^2
3.1. Counselee's acceptance.	**.84**		.73
3.2. Active listening 1.	**.93**		.86
3.3. Counselee-centered consultation.	**.76**		.56
3.4. Nondirectiveness 1.		**.88**	.83
3.5. Nondirectiveness 2.		**.91**	.85
3.6. Nondirectiveness 3.		**.88**	.75
3.7. Counselee-professional communication.	**.77**		.70
3.8. Active listening 2.	.54	.41	.62
3.9. Professional's expertise.	**.73**		.52
Total variance explained (%)	**49.7**	**22.6**	
Eigenvalue following rotation	**3.98**	**1.80**	
Cronbach's alpha	**.86**	**.88**	
Extraction method: Principal component analysis Rotation method: Oblimin with Kaiser normalization			
Rotation converged in 4 iterations			

Note. As a consequence of the existence of missing values in one or more scales, N = 105. Values were obtained from pattern matrix table. Items which were retained in the component of that column are in boldface. h^2 = Final communality estimate; C1 = Component one; C2 = Component two.

3.2.4. 'Potential Effects' Dimension.

PCA for 'potential effects' items yielded a two-component solution explaining 68.3% of the total variance.

The first component, with five items, was labelled as 'satisfaction' because the majority of its items are related to counselees' satisfaction and the meeting of their expectations. Example items included, "O que eu esperava desta consulta concretizou-se" (item 4.8.). This component accounted for 55.7% of the variance, corresponding to an eigenvalue of 5.57. The component loadings ranged between .63 and .85 (M = .79).

The second component, with five items, was defined as 'empowerment', given that all of its items are related to an improvement of counselee's abilities to cope, communicate and perceive or think about their disease. Example items included, "Sinto-me mais capaz

de utilizar os apoios e os recursos existentes para satisfazer as minhas necessidades" (item 4.3.). This component accounted for 12.6% of the variance, corresponding to an eigenvalue of 1.26. The component loadings ranged between .53 and .94 (M = .75).

The Cronbach's alpha for these components is .89 and .85, respectively (see Table 8) reflecting an acceptable internal consistency.

Table 8

Component loadings after rotation and items selection of the 'Potential Effects' dimension

	Component loadings		
Items	C1	C2	h^2
4.1. Disease knowledge improvement.	**.63**		.73
4.2. Doubts decrease.	**.77**		.65
4.3. Empowerment 1.		**.64**	.45
4.4. Coping with disease and/or risk.		**.84**	.71
4.5. Empowerment 2.		**.79**	.69
4.6. New perspectives.		**.94**	.76
4.7. Counselee-professional relationship.		**.53**	.58
4.8. Expectations meeting.	**.79**		.79
4.9. Satisfaction 1.	**.92**		.85
4.10. Satisfaction 2.	**.85**		.60
Total variance explained (%)	**55.7**	**12.6**	
Eigenvalue following rotation	**5.57**	**1.26**	
Cronbach's alpha	**.89**	**.85**	
Extraction method: Principal component analysis Rotation method: Oblimin with Kaiser normalization			
Rotation converged in 8 iteration			

Note. As a consequence of the existence of missing values in one or more scales, N = 103. Values were obtained from pattern matrix table. Items which were retained in the component of that column are in boldface. h^2 = Final communality estimate; C1 = Component one; C2 = Component two.

3.2.5. 'Services Provision' Dimension.

In a first PCA, item 5.5. was eliminated because it cross-loaded on both components and clinically was not considered an indispensable quality indicator. Moreover, as the item

1.10. also measures the use of audiovisual and didactic material, this elimination did not mean a real loss of a quality indicator.

A second PCA yielded a two-component solution, however, given the eigenvalue of the third component (.99) it was decided to repeat the analysis but forcing the program to extract three components. This analysis resulted in three components that explained in combination 69.9% of the total variance (see Table 9 for detailed results).

The first component, with five items, was defined as 'services organization' because all of its items are related to services characteristics that reflect its general organization, such as the existence of a multidisciplinary team. Example items included, "Um aspeto importante deste serviço é a existência de uma equipa de profissionais de áreas distintas" (item 5.8.). This component accounted for 38.7% of the variance, corresponding to an eigenvalue of 3.48. The component loadings ranged between .63 and .87 (M = .77).

The second component, with two items, was labelled as 'preparation of the counselee for the consultation' given that both items represent services strategies to prepare the counselee for the consultations. Example items included, "Fui previamente contactado telefonicamente para preparar a consulta" (item 5.2.). This component accounted for 20.2% of the variance, corresponding to an eigenvalue of 1.82. The component loading of both items was .96.

Cronbach's alphas of .80 and .93 for both components indicate that these have a good internal consistency (Field, 2013).

The third component, with two items, was named as 'time management' because both items are related to time aspects, such as the waiting time for the test result communication. Example items included, "O tempo de espera pela comunicação dos resultados foi o previsto" (item 5.7.). This component accounted for 11% of the variance, corresponding to an eigenvalue of .99. Item 5.4 cross-loaded on all components but it was decided to retain this item on this component, with which it is more clearly related in a conceptual perspective, therefore facilitating the component interpretation. The component loadings were of .35 (item 5.4.) and .94 (item 5.7.). Given the clinical relevance of these two items and its theoretical consistency together it was decided to retain this component in spite of its lower eigenvalue and Cronbach's alpha (.35).

Table 9

Component loadings after rotation and items selection of the 'services provision' dimension

	Component loadings			
Items	C1	C2	C3	h^2
5.1. Consultation duration.	**.77**			.62
5.2. Consultation preparation 1.		**.96**		.91
5.3. Consultation preparation 2.		**.96**		.93
5.4. Time management 1.	.46	.15	**.35**	.46
5.5. Audiovisual and didactic materials.		.46	.39	.42
5.6. Privacity.	**.79**			.70
5.7. Time management 2.			**.94**	.88
5.8. Clinical team muldisciplinarity.	**.87**			.72
5.9. Openness for other family members.	**.63**			.48
5.10. Openness for future contacts.	**.79**			.60
Total variance explained (%)	**38.7**	**20.2**	**11**	
Eigenvalue following rotation	**3.48**	**1.82**	**.99**	
Cronbach's alpha	**.80**	**.93**	**.35**	
Extraction method: Principal component analysis Rotation method: Oblimin with Kaiser normalization				
Rotation converged in 5 iterations				

Note. As a consequence of the existence of missing values in one or more scales, $N = 102$. Values were obtained from pattern matrix table. Items which were retained in the component of that column are in boldface. h^2 = Final communality estimate; C1 = Component one; C2 = Component two; C3 = Component three.

3.3. Construct Validity

In general, all dimensions were significantly ($p < .001$), positively and moderately ($.42 \leq r$ of all dimensions $\leq .74$) correlated with each other as expected, providing evidence of construct validity (see Table 10 for detailed results). A strong correlation was found between the 'counselee's individual attributes' dimension and the 'counselee's knowledge and understanding' dimension ($r = .74$). A similar correlation was found between 'counselee's individual attributes' dimension and 'potential effects' dimension ($r = .73$). However, correlations with the 'services provision' dimension were not as strong ($.42 \leq r$ of 'services provision dimension' with the remaining dimensions $\leq .49$), with the exception of the 'potential effects' dimension with which it had a Pearson's r of .61.

Table 10

Correlations between the scale dimensions

		1	2	3	4	5	6
1.	Counselee's education						
2.	Counselee's understanding and knowledge	.67**					
3.	Counselee's individual attributes	.67**	.74**				
4.	Relationship and communication issues	.49**	.55**	.62**			
5.	Potential effects	.49**	.69**	.73**	.65**		
6.	Services provision	.42**	.53**	.49**	.48**	.61**	

Note.

**Correlation is significant at the .01 level.

3.4. Reliability

Almost all dimensions presented acceptable levels of internal consistency in this sample, presenting values equal or higher than the reference values of .70 and .80 ($.70 \leq \alpha$ of all dimensions $\leq .90$), with the exception of the dimension 'counselee's understanding and knowledge' which presented an alpha value of .60 (see Appendix E for detailed results). In general, the deletion of the majority of items did not appreciably improve the internal consistency and almost all items have an item-total correlation above .3, with the exception of items 1.1. and 1.10.. Even though these items contribute to decreasing the internal consistency of the dimension, they were not eliminated given their clinical relevance as fundamental quality indicators of a GC consultation.

3.5. Items Sensitivity

In general, the items presented absolute values of skewness and kurtosis above |1|, indicating the presence of a non-normal distribution (see Appendix F for detailed results). The analysis of the distribution of the responses for each item revealed the presence of a ceiling effect (see Appendix G for detailed results).

IV. Discussion

The present study was aimed at developing and validating a new multidimensional scale to assess counselees' evaluation of GC quality, thereby fulfilling a demand of the professionals and CGS.

On the whole, results indicated that this scale is a valid and reliable tool. Current findings are in general aligned with the components found in scale for professionals and REM components (Costa, 2017; Paneque et al., 2018; McCarthy Veach et al., 2007). New, however, is the finding of the components - 'counselee-centred care' and 'time management'.

The emergence of the component 'counselee-centred care' is in line with the international guidelines and numerous studies in the field of healthcare which emphasize the patient-centred care as a quality standard in healthcare and a fundamental dimension of the broader concept of high-quality healthcare (e.g., Institute of Medicine [IOM], 2001). In addition, the identification of this component highlights the value that the counselees place on receiving care that is respectful of and responsive to their needs, preferences and values (IOM, 2001). Which is consistent with much of the counselees literature reviewed in the first chapter (Bernhardt et al., 2000; Costal Tirado et al., 2017; Paneque et al., 2015a; Skirton, 2001). The identification of 'time management' is also aligned with the literature about the evaluation of the quality of healthcare (IOM, 2001; Stalk & Hout, 1990). According to IOM (2001), the "timeliness" or time management is an important dimension of quality of healthcare. For Stalk and Hout (1990) time management is not only a competitive advantage for a healthcare service but also an essential aspect for the patient since timing might influence the treatment prescribed and ultimately even the patient survival (Stalk & Hout, 1990). This is also congruent with the counselees literature reviewed in the first chapter (Bernhardt et al., 2000; Guimarães et al., 2013; McAllister et al., 2008b; Paneque et al., 2012).

Confirming the importance of the psychosocial factors in the GC, components such as 'emotional experience, motivations and decision-making support', 'counselee-centred care', 'counselee-professional relationship' and 'counselee's acceptance' were identified. Moreover, components such as 'meaningful understanding' and 'strategies to facilitate counselee's understanding' were found. Further confirming the value that the counselees attribute to receive personalized care and be actively involved in the GC process. These

findings further support the validity of the scale, as they are in accordance with published studies about the counselees' perspective of GC (e.g.,, Bernhardt et al., 2000; Guimarães et al., 2013; MacLeod et al., 2002).

Providing further evidence of the validity of the scale, values of total variance explained of the components, as well as component loadings, and components reliability were, in general, all good. Nevertheless, the performance of the items 1.1. and 5.4., and the components 'to identify additional resources', 'meaningful understanding', 'strategies to facilitate counselee's understanding' and 'time management' should be further examined in future studies.

At item level, the five new items introduced in this scale demonstrated adequate functioning, further confirming this adequacy as valuable quality indicators for counselees.

The construct validity of the scale was also supported in the correlation matrix analysis. The dimensions are significantly, positively and moderately correlated demonstrating that they are related but separated toward measuring different dimensions of a single global construct – GC quality. Regarding the correlations found, the stronger correlation between 'counselee's individual attributes' and 'counselee's knowledge and understanding'(r = .74) is congruent with the findings reported in previous studies (e.g., Guimarães et al., 2013; Macleod et al., 2002; McCarthy Veach et al., 2007). Supporting the association between the adaptation of the information to the counselees' needs, expectations, personal and interpersonal characteristics, and previous knowledge and the counselee's understanding. The correlation between 'counselee's individual attributes' and 'potential effects' (r = .73) is also convergent with the conclusions of Guimarães and colleagues (2013) as well as with the findings previously reported on the general medical literature (e.g., Internacional Alliance of Patients' Organizations, 2007). Further confirming the association between a more personalized and counselee-centred approach and the patient's health outcomes and levels of satisfaction. The lower correlations presented by the dimension 'services provision' were also expected because in contrast to the other dimensions the 'services provision' is not originally part of REM. As well as the moderate correlation between the 'services provision' dimension and 'potential effects' dimension is not surprising (r = .61). Given that other authors, such as McAllister and colleagues (2008) have already claimed that some attributes related to services provision may contribute to maximizing counselees' benefits and outcomes. This correlation, in turn, demonstrates the pertinence of the integration of this dimension in this scale.

In terms of reliability, the scale presented acceptable values of internal consistency (.70 ≤ α of all dimensions ≤ .90), with the exception of the dimension 'counselee's understanding and knowledge' (.60). According to Nunnally (1978), this can be also considered as an acceptable value for first reliability analysis.

Regarding the items sensitivity, the results are consistent with findings reported previously in the validation study of the scale for professionals (Costa, 2017). Considering the results previously reported with similar counselee's samples (Bleiker et al., 1997; Reynolds, Puck, & Robinson, 1974; McCarthy Veach et al., 1999), these results may not mean a problem in the sensitivity of the items, but rather to reflect the counselees' high level of satisfaction with the GC quality. Percentages of participants who answered using the upper (5) and intermediate (4) points of the Likert scale further support this hypothesis (see Appendix G for detailed results). Many potential causes may be advanced to explain this high degree of satisfaction with the GC. The CGS, which agreed to participate in the study, may offer in fact a high-quality service. Then the GC consultations are different from the typical medical consultations in terms of content, organization and duration. For example, the informational but also the emotional needs of the counselees are addressed. The professional usually give time for counselees to express their doubts and feelings about the disease and test. Moreover, in the case of a pre-symptomatic test (PST), the counselees receive besides the pre and post GC, a consultation with a psychologist before taking the decision about the genetic test. Other factors more related to the individual experience of the counselees, such as the meeting of their expectations of GC (e.g., Davey et al., 2005; Michie, Marteau, & Bobrow, 1997), the quality of the relationship established with the professional (e.g., MacLeod et al., 2002; Skirton, 2001) and the quality of the communication with the professional during the consultation (e.g., Meiser, Irle, Lobb, & Barlow-Stewart, 2008) could additionally contribute to their degree of satisfaction. These potential causes may aid to explain the high degree of satisfaction with GC quality found, but additional research is needed. In future studies, the analyses of the sensitivity of the items should be replicated with other samples. Indeed, despite the medium size of this sample, the number of CGS involved in this study is relatively small ($N = 4$).

Comparing these findings with those found on the scale for professionals assessment of GC quality, a future comparison between the data collected from both scales seems to be possible. However, it is worth noticing that some differences were found. Concerning the 'genetic education', compared with professionals, counselees more clearly separate the

provision of information from its understanding. Regarding the 'counselee's individual attributes', counselees do not split so clearly the emotional experience of the motivations approach and decision-making support. Moreover, for the counselees the items "A consulta foi organizada de forma a responder às minhas necessidades", "O profissional perguntou-me e compreendeu o(s) motivo(s) do meu pedido de consulta" and "Tive a oportunidade de dar o meu consentimento informado" are more strongly associated with each other than with the remaining items. In respect of the potential effects, counselees more clearly separate the empowerment from the satisfaction, associating interestingly the items "Na consulta fiquei a saber mais sobre a doença e os aspetos relacionados" and "Ao longo da consulta as minhas dúvidas diminuíram" with the set of items related to the satisfaction. With regard to the services provision, for the counselees, the items "O tempo de espera pela consulta foi razoável" and "O tempo de espera pela comunicação dos resultados foi o previsto" are more strongly associated with each other than with the remaining items. These differences in the organization of the items resulted in the emergence of new components specific from the counselees' perspective, namely the 'counselee-centred care', 'satisfaction' or 'time management'. Different hypothesis may be advanced to explain these discrepancies. Firstly, the counselees and the professionals are answering the scale items from different perspectives, the counselees are evaluating the care received while the professionals are assessing their own practice. Then the respondents' personality characteristics and their assumptions about the GC and its quality, as well as their expectations of the GC may also contribute to these differences. Looking specifically to the counselees' characteristics, their health literacy and educational level may have influenced their comprehension and consequent evaluation of the items. Moreover, other factors, such as the counselees' personal opinion of the professional who conducted the consultation, or their personal general impression of the hospital in which consultation taken place may also contribute to explaining these differences (Donabedian, 2005). It is also worth recognizing that some specific characteristics of the scales may have influenced these results. Further research with the combined application of both scales should be conducted to understand better these differences.

In sum, the results of this study present preliminary evidence that the scale has adequate psychometric proprieties, namely construct validity and internal consistency. These results demonstrate that the scale may be used to measure how counselees evaluate the quality of GC and support the suitability of the REM as a useful conceptual framework

to evaluate the GC quality, as well as the content validity and cultural adequacy of the quality indicators selected. Representing an important addition to the empirical support obtained previously for this model and these quality indicators by Paneque and colleagues (2018).

5.1. Strengths and limitations

This scale is the first Portuguese measure of the counselee's assessment of GC quality. The scale items were developed and refined through rigorous procedures of literature review and cognitive interview with members of the target population, in order to ensure their content and face validity. The decisions made in testing the scale structure, reliability and validity were clearly explained and followed empirical, theoretical and clinical criteria. The scale can be easily and quickly administered, which is an advantage in a healthcare context where time constraints are well-known.

Some limitations of the present study must be acknowledged and taken into account in results interpretation.

First, it should be noted that despite the empirical validation design being a strength of this study, the sample may be considered of medium size. Moreover, the generalizability of the findings may be limited by the potential response bias and lack of representativeness of the final sample. The sample is not representative of the broader Portuguese counselee's population because not all national CGS had the opportunity to participate in the study. It is also possible to hypothesize that those which accepted to participate may be more concerned with the quality issues in their practice. Another limitation is that the sample was over-represented by women and by counselees who had a GC consultation within the predictive/presymptomatic setting, with a lower number of counselees who had a GC consultation in other clinical settings. It is not known whether or not this reflects the profile of the majority of GC consultations in Portugal because for ethical reasons, we could not collect any data from counselees who declined to participate. Furthermore, as information concerning participants who chose not to participate in the study was not collected, the participants included in this sample may have a greater interest in their health and healthcare quality, higher health literacy and higher expectations to their GC consultation than the general counselees. The use of the words "quality evaluation", and the subsequent

perception of being evaluating the professionals and services performance, may have also biased counselee's answers.

Secondly, responses were not collected through the online version of the scale. This is consistent with findings reported previously in studies that compared data obtained by using different modes of administration of surveys (Nulty, 2008; Basílio et al., 2017). Nevertheless, it might be interesting for future studies to reflect on the reasons for counselees preference to answering to the paper version of the scale rather than to the online version, and potential strategies to increase the response rate to the online version.

Thirdly, the scarcity of other measures validated with Portuguese counselees restricted the choice of variables that could be used as a reference to construct and external validity examination.

Fourthly, confirmatory factor analysis and additional discriminant and convergent validity evidence may be useful to explore the structure and psychometric properties of the scale in more depth (Field, 2013). The use of a larger sample and the inclusion of counselees who had a GC consultation in other clinical contexts such as preconceptional and pre-natal, which are underrepresented in this sample, may be useful to further confirm the scale validity.

Finally, in spite of the evidence of validity and reliability globally obtained in this study, further exploration of some items, which presented lower communality values and/or component loadings, may be worthwhile. The use of qualitative methodologies might be pertinent to understand more fully why those items did not present such good statistical results.

5.2. Implications for Research and Practice and Recommendations for Future Studies

The current study offers relevant contributions to the field of GC quality. Results showed that this instrument seems useful both in research and practice contexts.

This is the first known scale for quality assessment by counselees which used REM as theoretical background and which is not exclusively focused on specific GC processes or effects. So this scale should facilitate future research in GC quality, allowing a better understanding of how counselees perceive GC process, which process aspects may affect the potential effects of GC, which are the more valued quality indicators across clinical settings, as well as the identification of training needs for professionals, or potential

additions to education curriculum of GC professionals. The knowledge gained from this scale application may then be used to improve the quality assessment routines at national services, to develop strategies to increase services support to the counselees and clinical interventions to maximize counselee's benefits. The clinical usefulness of the scale was already recognized by national CGS, which accepted promptly to participate in the data collection.

Finally, in the near future, it would be essential to define both procedures to calculate the scale scores and cut-off values to identify a GC with high quality. Later, when the services begin to use the scale, it would be important to examine the scale performance, as well as to continue its validation process, particularly by testing it in other counselee samples, as well as across countries and languages. Furthermore, as findings of this study are generally congruent with those previously obtained in the professionals' scale validation study (Costa, 2017; Paneque et al., 2018), in the future, this line of research may be continued by testing and studying the combined application of both scales (professionals and counselees) aiming to achieve a comprehensive evaluation system of GC quality.

V. Conclusions

In conclusion, the results of psychometric validation of the first Portuguese tool for assessing GC quality in a sample of Portuguese counselees who had a GC consultation in different clinical settings provide evidence that this scale is a valid and reliable tool, encouraging its application in clinical and research contexts.

The development and validation of this scale is another step in the integration of the counselees' perspective into the discussion of GC quality, providing a tool to investigate the counselees' understanding of GC. Moreover, the scale provides new quality indicators specifically designed for counselees, based on scientific evidence and current clinical practices that can be useful for other researchers interested in monitoring the GC quality or study factors that influence the GC quality perception and its evaluation.

Finally, it is also important to mention that this scale meets a well-identified need of the national professionals and CGS, as well as the demand of the World Health Organization (WHO, 2008) for more-patient centred care and a continuous healthcare quality improvement.

References

Austin, J., Semaka, A., & Hadjipavlou, G. (2014). Conceptualizing genetic counselling as psychotherapy in the era of genomic medicine. *Journal of Genetic Counselling, 23*(6), 903-909. doi:10.1007/s10897-014-9728-1

Basílio, N., Cardoso, S., Nunes, J. M., Laranjo, L., Antunes, M. D. L., & Heleno, B. (2018). Portuguese primary care physicians response rate in surveys: A systematic review. *Revista da Associação Médica Brasileira, 64*(3), 272-280. doi:10.1590/1806-9282.64.03.272

Baty, B. J. (2018). Genetic counselling: Growth of the profession and the professional. *American Journal of Medical Genetics, Part C: Seminars in Medical Genetics, 178*(1), 54–62. doi:10.1002/ajmg.c.31601

Beatty, P. C., & Willis, G. B. (2007). Research synthesis: The practice of cognitive interviewing. *Public Opinion Quarterly, 71*(2), 287-311. doi: 10.1093/poq/nfm006

Berkenstadt, M., Shiloh, S., Barkai, G., Katznelson, M. B., & Goldman, B. (1999). Perceived personal control (PPC): A new concept in measuring outcome of genetic counselling. *American Journal of Medical Genetics, 82*(1), 53-59. doi:10.1002/(SICI)1096-8628(19990101)82:1<53::AID-AJMG11>3.0.CO;2-#

Bernhardt, B. A., Biesecker, B. B., & Mastromarino, C. L. (2000). Goals, benefits, and outcomes of genetic counselling: Client and genetic counsellor assessment. *American Journal of Medical Genetics, 94*(3), 189-197.

Bleiker, E. M. A., Aaronson, N. K., Menko, F. H., Hahn, D. E. E., van Asperen, C. J., Rutgers, E. J. T., … Leschot, N. J. (1997). Genetic counselling for hereditary cancer: A pilot study on experiences of patients and family members. *Patient Education and Counselling, 32*(1), 107–16.

Bryman, A., & Cramer, D. (2003). *Análise de dados em ciências sociais: Introdução às técnicas utilizando o SPSS para Windows*. Oeiras, Portugal: Celta Editora.

Costa, R. C. (2017). *Instrumento Português para Avaliação da Qualidade da Prática do Aconselhamento Genético: A Contribuição dos Profissionais dos Serviços de Genética Nacionais* (Master's thesis). Retrieved from https://repositorio-aberto.up.pt/

Costal Tirado, A., McDermott, A. M., Thomas, C., Ferrick, D., Harris, J., Edwards, A., & McAllister, M. (2017). Using patient-reported outcome measures for quality

improvement in clinical genetics: An exploratory study. *Journal of Genetic Counselling, 26*(5), 1017–1028. doi:10.1007/s10897-017-0079-6

Chou, A. F., Mulvihill, J., Kaye, C., Mann, S., Williams, M. S., & Williamson, L. (2018). Developing a genetic services assessment tool to inform quality improvement efforts in state genetic service delivery. *Genetics in Medicine,* 1-10. doi:10.1038/s41436-018-0141-2

Davey, A., Rostant, K., Harrop, K., Goldblatt, J., & O'Leary, P. (2005). Evaluating genetic counselling: Client expectations, psychological adjustment and satisfaction with service. *Journal of Genetic Counselling, 14*(3), 197–206. doi:10.1007/s10897-005-0519-6

DeMarco, T. A., Peshkin, B. N., Mars, B. D., & Tercyak, K. P. (2004). Patient satisfaction with cancer genetic counselling: A psychometric analysis of the genetic counselling satisfaction scale. *Journal of Genetic Counselling, 13*(4), 293-304. doi:10.1023/B:JOGC.0000035523.96133

Decreto-lei nº 12/2005 de 26 de Janeiro. *Diário da República nº 18/2005 – I Série A*. Lisboa: Assembleia da República.

Donabedian, A. (2005). Evaluating the quality of medical care. *The Milbank Quarterly: A Multidisciplinary Journal of Population Health and Health Policy, 42*(3), 166-203. doi:10.1111/j.1468-0009.2005.00397.x

Erblich, J., Brown, K., Kim, Y., Valdimarsdottir, H. B., Livingston, B. E., & Bovbjerg, D. H. (2005). Development and validation of a breast cancer genetic counselling knowledge questionnaire. *Patient Education & Counselling, 56*(2), 182–191. doi:10.1016/j.pec.2004.02.007

International Alliance of Patients' Organizations. (2007). *What is patient-centred healthcare? – A review of definitions and principles* (2nd ed.). Retrieved from: http://iapo.org.uk/sites/default/files/files/IAPO%20PatientCentred%20Healthcare%20Review%202nd%20edition.pdf.

Institute of Medicine. (2001). *Crossing the quality chasm: A new health system for the 21st century*. Washington, DC: National Academy Press.

Field, A. P. (2013). *Discovering statistics using IBM SPSS statistics: And sex and drugs and rock 'n' roll* (4th ed.). London, England: Sage.

Fraser, F. C. (1974). Current issues in medical genetics. *American Journal of Human Genetics, 26*(5), 636-659.

Guimarães, L., Sequeiros, J., Skirton, H., & Paneque, M. (2013). What counts as effective genetic counselling for presymptomatic testing in late-onset disorders? A study of the consultand's perspective. *Journal of Genetic Counselling, 22*(4), 437-447. doi:10.1007/s10897-012-9561-3

Lea, D. H. (1996). Emerging quality improvement measures in genetic counselling. *Journal of Genetic Counselling, 5*(3), 123–137. doi:10.1007/BF01408657

Leavy, P. (2017). *Research Design: Quantitative, qualitative, mixed methods, arts-based, and community-based participatory research approaches*. New York, NY: The Guildford Press.

Hartmann, J. E., McCarthy Veach, P., MacFarlane, I. M., & Leroy, B. S. (2015). Genetic counsellor perceptions of genetic counselling session goals: A validation study of the reciprocal-engagement model. *Journal of Genetic Counselling, 24*(2), 225-237. doi:10.1007/s10897-013-9647-6

MacLeod, R., Craufurd, D., & Booth, K. (2002). Patients' perceptions of what makes genetic counselling effective: An interpretative phenomenological analysis. *Journal of Health Psychology, 7*(2), 145–156. doi:10.1177/1359105302007002454

Madlensky, L., Trepanier, A. M., Cragun, D., Lerner, B., Shannon, K. M., & Zierhut, H. (2017). A rapid systematic review of outcomes studies in genetic counselling. *Journal of Genetic Counselling, 26*(3), 361-378. doi:10.1007/s10897-017-0067-x

Marôco, J. (2007). *Análise estatística com utilização do SPSS* (3ª ed.). Lisboa, Portugal: Edições Sílabo.

McAllister, M., Dunn, G., & Todd, C. (2011a). Empowerment: Qualitative underpinning of a new clinical genetics-specific patient-reported outcome. *European Journal of Human Genetics, 19*(2), 125–130. doi:10.1038/ejhg.2010.160

McAllister, M., Payne, K., MacLeod, R., Nicholls, S., Donnai, D., & Davies, L. (2008a). Patient empowerment in clinical genetics services. *Journal of Health Psychology, 13*(7), 895-905. doi:10.1038/ejhg.2010.160

McAllister, M., Payne, K., MacLeod, R., Nicholls, S., Donnai, D., & Davies, L. (2008b). What process attributes of clinical genetics services could maximize patient benefits?. *European Journal of Human Genetics, 16*(12), 1467-1476. doi:10.1038/ejhg.2008.121

McAllister, M., Wood, A., Dunn, G., Shiloh, S., & Todd, C. (2011b). The Genetic Counselling Outcome Scale: A new patient-reported outcome measure for clinical genetics services. *Clinical Genetics, 79*(5), 413-424. doi:10.1111/j.1399-0004.2011.01636.x

McCarthy Veach, P., Truesdell, S. E., LeRoy, B. S., & Bartels, D. M. (1999). Client perceptions of the impact of genetic counselling: An exploratory study. *Journal of Genetic Counselling, 8*(4), 191–216. doi:10.1023/A:1022946431820

McCarthy Veach, P., Bartels, D. M., & Leroy, B. S. (2003). *Facilitating the genetic counselling process: A practice manual*. New York, NY: Springer.

McCarthy Veach, P., Bartels, D. M., & LeRoy, B. S. (2007). Coming full circle: A reciprocal-engagement model of genetic counselling practice. *Journal of Genetic Counselling, 16*(6), 713–728. doi:10.1007/s10897-007-9113-4

Meiser, B., Irle, J., Lobb, E., & Barlow-Stewart, K. (2008). Assessment of the content and process of genetic counselling: A critical review of empirical studies. *Journal of Genetic Counselling, 17*(5), 434-451. doi:10.1007/s10897-008-9173-0

Mesters, I., van den Borne, H., McCormick, L., Pruyn, J., de Boer, M., & Imbos, T. (1997). Openness to discuss cancer in the nuclear family: Scale, development, and validation. *Psychosomatic Medicine, 59*(3), 269–279. doi:10.1097/00006842-199705000-00010

Michie, S., Marteau, T., & Bobrow, M. (1997). Genetic counselling: The psychological impact of meeting patients' expectations. *Clinical Genetics, 34*(3), 237–241. doi:10.1136/jmg.34.3.237

Michie, S., Dormandy, E., & Marteau, T. M. (2002). The multi-dimensional measure of informed choice: A validation study. *Patient Education and Counselling, 48*(1), 87–91. doi:10.1016/S0738-3991(02)00089-7

Nulty, D. D. (2008). The adequacy of response rates to online and paper surveys: What can be done?. *Assessment & Evaluation in Higher Education, 33*(3), 301-314. doi:10.1080/02602930701293231

Nunnally, J. C. (1978). *Psychometric theory* (2nd ed.). New York, NY: McGraw Hill.

Ormond, K. E., Laurino, M. Y., Barlow-Stewart, K., Wessels, T. M., Macaulay, S., Austin, J., & Middleton, A. (2018). Genetic counselling globally: Where are we now?. *American Journal of Medical Genetics, Part C: Seminars in Medical Genetics, 178*(1), 1-10. doi:10.1002/ajmg.c.31607

Paneque, M., Costa, C., Lemos, C., Alves-Ferreira, M., Sequeiros, J., & Lemos, M. S. (2018). Proposta de uma escala portuguesa para a avaliação da qualidade do aconselhamento genético: Uma nova ferramenta para os profissionais da saúde. *Acta Médica Portuguesa, 31*(6), 321-328. doi:10.20344/amp.9997

Paneque, M., Mendes, Á., Guimarães, L., Sequeiros, J., & Skirton, H. (2015a). Genetics health professionals' views on quality of genetic counselling service provision for presymptomatic testing in late-onset neurological diseases in Portugal: Core components, specific challenges and the need for assessment tools. *Journal of Genetic Counselling, 24*(4), 616–625. doi:10.1007/s10897-014-9784-6

Paneque, M., Mendes, Á., Saraiva, J., & Sequeiros, J. (2015b). Genetic counselling in Portugal: Education, practice and a developing profession. *Journal of Genetic Counselling, 24*(4), 548–552. doi:10.1007/s10897-015-9827-7

Paneque, M., Sequeiros, J., & Skirton, H. (2012). Quality assessment of genetic counselling process in the context of presymptomatic testing for late-onset disorders: A thematic analysis of three review articles. *Genetic Testing and Molecular Biomarkers, 16*(1), 36–45. doi:10.1089/gtmb.2011.0023

Payne, K., Nicholls, S. G., McAllister, M., MacLeod, R., Ellis, I., Donnai, D., & Davies, L. M. (2007). Outcome measures for clinical genetics services: A comparison of genetics healthcare professionals and patients' views. *Health Policy, 84*(1), 112–122. doi:10.1016/j.healthpol.2007.03.005

Payne, K., Nicholls, S., McAllister, M., MacLeod, R., Donnai, D., & Davies, L. M. (2008). Outcome measurement in clinical genetics services: A systematic review of validated measures. *Value in Health: the journal of the International Society for Pharmacoeconomics and Outcomes Research, 11*(3), 497-508. doi:10.1111/j.1524-4733.2007.00259.x

Pilnick, A. (2002). 'There are no rights and wrongs in these situations': Identifying interactional difficulties in genetic counselling. *Sociology of Health and Illness, 24*(1), 66-88. doi:10.1111/1467-9566.00004

Pilnick, A., & Dingwall, R. (2001). Research directions in genetic counselling: A review of the literature. *Patient Education and Counselling, 44*(2), 95-105.

Pithara, C. (2014). Identifying outcomes of clinical genetic services: Qualitative evidence and methodological considerations. *Journal of Genetic Counselling, 23*(3), 229-238. doi:10.1007/s10897-013-9654-7

Rantanen, E., Hietala, M., Kristoffersson, U., Nippert, I., Schmidtke, J., Sequeiros, J., & Kääriäinen, H. (2008). What is ideal genetic counselling? A survey of current international guidelines. *European Journal of Human Genetics, 16*(4), 445-452. doi:10.1038/sj.ejhg.5201983

Redlinger-Grosse, K., McCarthy Veach, P., Cohen, S., LeRoy, B. S., MacFarlane, I. M., & Zierhut, H. (2016). Defining our clinical practice: The identification of genetic counselling outcomes utilizing the reciprocal-engagement model. *Journal of Genetic Counselling, 25*(2), 239–257. doi:10.1007/s10897-015-9864-2

Reed, S. C. (1974). A short history of genetic counselling. *Social Biology, 21*(4), 332-339. doi:10.1080/19485565.1974.9988131

Reynolds, B. D., Puck, M. H., & Robinson, A. (1974). Genetic counselling: An appraisal. *Clinical Genetics, 5*(3), 177-187. doi:10.1111/j.1399-0004.1974.tb01680.x

Resta, R. G. (2006). Defining and redefining the scope and goals of genetic counselling. *American Journal of Medical Genetics, Part C: Seminars in Medical Genetics, 142C*(4), 269-275. doi:10.1002/ajmg.c.30093

Schmidlen, T., Sturm, A. C., Hovick, S., Scheinfeldt, L., Scott Roberts, J., Morr, L., … Sweet, K. (2018). Operationalizing the reciprocal-engagement model of genetic counselling practice: A framework for the scalable delivery of genomic counselling and testing. *Journal of Genetic Counselling, 27*(5), 1111-1129. doi:10.1007/s10897-018-0230-z

Skirton, H. (2001). The client's perspective of genetic counselling - A grounded theory study. *Journal of Genetic Counselling, 10*(4), 329–331. doi:10.1023/a:1016677110500

Skirton, H., Parsons, E., & Ewings, P. (2005). Development of an audit tool for genetic services. *American Journal of Medical Genetics, 136*(2), 122-127. doi:10.1002/ajmg.a.30711

Stalk, G., & Hout, T. M. (1990). *Competing against time: How time-based competition is reshaping global markets*. New York, NY: Free Press.

Tabachnick, B. G., & Fidell, L. S. (2012). *Using multivariate statistics* (6th ed.). Boston, MA: Pearson.

Wang, C., Gonzalez, R., & Merajver, S. D. (2004). Assessment of genetic testing and related counselling services: Current research and future directions. *Social Science & Medicine, 58*(7), 1427-1442. doi:10.1016/S0277-9536(03)00337-X

Willis, G. B. (2015). *Analysis of the cognitive interview in questionnaire design: Understanding qualitative research*. New York, NY: Oxford University Press.

World Health Organization. (2008). *The world health report 2008: primary health care now more than ever* (Report No. WHO/IER/WHR/08.1). Retrieved from: http://www.who. int/whr/2008/en/

Appendix A. Summary of the main tools used in genetic counselling assessment

Tool	Author(s) and Publication's Year	Source	Description
Clinical Genetics Services			
Audit tool for Genetic Services (AWMGS)	Skirton, Parsons, & Ewings (2005)	EBSCO	**Aim:** To Audit the clinical genetics services. **Dimensions:** (1) enhanced understanding; (2) positive psychological change; (3) respect for autonomy; (4) adaptation; (5) disequilibrium; and (6) value of contact. **Sample of validation:** 97 clients of a clinical genetics service. **Reliability estimates:** Not reported.
Instrument for internal assessment of the quality of genetic counselling within a genetic counselling	EuroGentest, Unit3 (2010)	EBSCO	**Aim:** Internal assessment of the quality of genetic counselling within a genetic counselling clinic. This a measure created to the GC professionals. **Dimensions:** (1) size of and collaboration in the unit; (2) staff education; (3) physical environment and access; (4) waiting times; (5) prerequisite of counselling; (6) language, culture and communication; (7) decision-making process and consent; (8) counselee experience; (9) extended support; (10) post-consultation measures; and (11) guidelines. **Reliability estimates:** Not reported.
Genetic counselling Outcome Scale (GCOS-24)	McAllister, Wood, Dunn, Shiloh, & Todd (2011)	EBSCO	**Aim:** To evaluate clinical genetics services. **Number of items**: 24. **Sample of validation:** 527 individuals who are affected by a genetic condition, or they are at-risk, or they are parents of a son with a genetic condition, or they are parents at-risk for having an affected child. **Reliability estimates:** .86.
Decision-Making			
Multidimensional Measure of Informed	Michie, Dormandy, & Marteau (2002)	EBSCO	**Aim:** To assess if women made an informed decision.

Choice (MMIC)			**Dimensions:** (1) Knowledge about prenatal screening; (2) attitude towards screening; and (3) actual decision. **Sample of validation:** 225 women who received low-risk results following serum screening for Down syndrome. **Reliability estimates:** Ranges from .68 to .78.
Familial Communication			
Openness to Discuss Hereditary Cancer in the Family (ODCF) Scale	Mesters, Van Den Borne, Mccormick, Pruyn, De Boer, & Imbos (1997)	EBSCO	**Aim:** To evaluate the openness to discuss cancer within the family. **Number of items**: 8 items. **Sample of validation**: 498 individuals with either breast cancer or Hodgkin's disease and 133 individuals with cancer in the head and neck. **Reliability estimates:** Ranges from .78 to .92.
Family Communication Questionnaire (FCQ)	Hughes, Lerman, Schwartz, Peshkin, Wenzel, Narod, Corio, Tercyak, Hanna, Isaacs, & Main (2002)	EBSCO	**Aim:** To assess family communication about genetic testing. **Dimensions: (**1) communication of BRCA1/2 test results; (2) length of time between receipt of BRCA1/2 test result and communication with relatives; (3) motivations for communicating BRCA1/2 test results and motivations for not communicating BRCA1/2 test results; and (4) topics discussed with family members. **Sample of validation:** 43 women who were the first family member to have genetic testing. **Reliability estimates:** Not reported.
Informing Relatives Inventory (IRI)	Geus, Aalfs, Menko, Sijmons, Verdam, Haes, & Smets (2015)	EBSCO	**Aim:** To assess counselee's knowledge, motivation, and self-efficacy regarding the disclosure of hereditary cancer risk information to at-risk relatives. **Dimensions:** This is a battery of instruments that evaluate the following constructs: (a) counselee's knowledge, (b)

			motivation, and (c) (c) self-efficacy regarding the disclosure of hereditary cancer risk information to at-risk relatives. **Sample of validation:** 212 counselee's visiting the Clinical Genetics department with regarding hereditary breast and/or ovarian cancer or colon cancer. **Reliability estimates:** Ranges from .82 to .90.
Knowledge			
Measure of Counselee's Knowledge of Down Syndrome	Braitman & Antley (1978)	EBSCO	**Aim:** To assess knowledge and understanding of Down syndrome before and after genetic counselling. **Dimensions:** (1) genetic knowledge; (2) recurrence risk; and (3) prenatal diagnosis. **Sample of validation:** 126 individuals - nurses, graduate students in Medical Genetics, special education teachers, and parents of children with Down syndrome. **Reliability estimates: .**84.
Maternal Serum Screening Knowledge Questionnaire (MSSKQ)	Goel, Glazier, Holzapfel, Pugh, & Summers (1996)	EBSCO	**Aim:** To assess knowledge about maternal serum screening (MSS). **Dimensions:** (1) Knowledge of test characteristics; (2) indications for screening and timing; (3) ancillary tests; and (4) and target conditions. **Sample of validation:** 1084 women attending a maternal registration clinic. **Reliability estimates:** .74.
Knowledge of Prenatal Screening and Diagnostic Tests	Marteau, Johnston, Plenicar, Shaw, & Slack (1998)	EBSCO	**Aim:** To assess women's knowledge about genetic tests that may be offered to them during their pregnancies. **Number of items:** 15 items divided in two parts: (1) familiarity and (2) knowledge. **Sample of validation:** 229 pregnant women, 69 women who had recently given birth, and 41 women who had never been pregnant. **Reliability estimates:** Ranges from .72 to

			.85.
Genetic Knowledge Index	Furr & Kelly (1999)	EBSCO	**Aim:** To measure basic genetic knowledge. **Number of items:** 5 items. **Sample of validation:** 330 individuals of the general population. **Reliability estimates:** .74.
Breast Cancer and Hereditary Knowledge Scale (BCHK)	Ondrusek, Warner, & Goel (1999)	EBSCO	**Aim:** To measure the general knowledge about breast cancer and hereditary breast cancer (HBC) among women at low to moderate risk of HBC. **Number of items:** 11 items. **Sample of validation**: 36 women breast clinic patients and 11 women of the general population. **Reliability estimates:** Not reported.
Breast Cancer Genetic Counselling Knowledge Questionnaire (BGKQ)	Erblich, Brown, Kim, Valdimarsdottir, Livingston, & Bovbjerg (2005)	EBSCO	**Aim:** To evaluate the knowledge of information typically included in genetic counselling for breast cancer. **Number of items:** 27 items. **Sample of validation**: 45 individuals of the general population and 28 women who had attending genetic counselling consultations. **Reliability estimates:** .92.
Measuring Genetic Knowledge: A Brief Survey Instrument for Adolescents and Adults	Fitzgerald-Butt, Bodine, Fry, Ash, Zaidi, Garg, Gerhardt, & McBride (2016)	EBSCO	**Aim:** To assess the Basic knowledge of genetics. **Number of items:** 18 items divided into 2 factors: (1) applied and (2) basic. **Sample of validation:** 465 parents of children with congenital heart defects and 196 adolescents and young adults with congenital heart defects. **Reliability estimates:** Ranges from .66 to .73.
Needs and Expectations			
QUOTE-gene[ca]	Pieterse, Van Dulmen, Ausems, Schoemaker, Beemer, & Bensing (2005)	EBSCO	**Aim:** To evaluate both counselee's needs and preferences in genetic counselling for a hereditary cancer. **Dimensions:** (1) determination and meaning of being a carrier of a cancer gene; (2)

			emotional aspects for counselee and family; (3) own risk of developing cancer; and (4) hereditary cancer in general. **Sample of validation:** 200 counselees referred for hereditary cancer, aged 18 years or older and being the first in the family seeking genetic counselling. **Reliability estimates:** Not reported.
Parents' Attitudes			
Pediatric BRCA1/2 Testing Attitudes Scale (P-TAS)	Peshkin, DeMarco, Garber, Valdimarsdottir, Patenaude, Schneider, Schwartz, & Tercyak (2009)	EBSCO	**Aim: assess** To measure parents' attitudes and interests in pediatric BRCA1/2 testing. **Dimensions:** (1) attitudes and beliefs, and (2) decision-making and communication. **Sample of validation:** 187 mothers after pretest genetic counselling and provision of a blood sample for BRCA1/2 testing and 96 mothers non-tested. **Reliability estimates:** Ranges from .70 to .80.
Perceived Personal Control			
Perceived Personal Control (PCP)	Berkenstadt, Shiloh, Barkay, Katznelson, & Goldman (1999)	EBSCO	**Aim:** To measure counselee's subjective perceptions of how much control they consider they have over their genetic problem. **Dimensions:** (1) cognitive control; (2) decisional Control; and (3) behavioural control **Sample of validation**: 256 individuals that are attending a clinical genetics service due a genetic condition. **Reliability estimates:** Ranges from .83 to .86.
Psychological Adjustment			
Multidimensional Impact of Cancer Risk Assessment Questionnaire (MICRA)	Cella, Hughes, Peterman, Chang, Peshkin, Schwartz, Wenzel, Lemke, Marcus, & Lerman (2002)	EBSCO	**Aim:** To evaluate the impact of result communication after a genetic testing. **Dimensions:** (1) distress; (2) uncertainty; and (3) positive experiences. **Sample of validation:** 158 women, at-risk for a BRCA1 or BRCA2 mutation, who are

			attending genetic counselling consultations. **Reliability estimates:** Ranges from .75 to .86.
Psychological adaptation to Genetics information Scale (PAGIS)	Read, Perry, & Duffy (2005)	EBSCO	**Aim:** To measure the psychological adaption to genetics information. **Dimensions:** (1) nonintrusiveness, (2) support, (3) self-worth, (4) certainty, and (5) self-efficacy. **Sample of validation:** 323 individuals with a genetic disease or members of a family with a genetic disease. **Reliability estimates:** .90.
Psychosocial Aspects of Hereditary Cancer (PAHC) Questionnaire	Eijzenga, Bleiker, Hahn, Kluijt, Sidharta, Gundy, & Aaronson (2014)	EBSCO	**Aim:** To evaluate specific psychosocial problems related to cancer genetic counselling **Dimensions:** (1) genetics, (2) practical issues, (3) family, (4) living with cancer, (5) emotions, and (6) children. **Sample of validation:** 127 counselees who are attending genetic counselling consultations. **Reliability estimates:** Not reported.
Quality			
Portuguese Tool for Quality Assessment of Genetic counselling: a New Tool for Healthcare Professionals	Paneque, Costa, Lemos, Alves-Ferreira, Sequeiros, & Lemos (2018)	EBSCO	**Aim:** Health Professionals working in genetic counselling field (auto) evaluate the quality of their practice. **Dimensions:** (1) education; (2) counselee's characteristics; (3) counsellor-counselee relationship; (4) effects of the process in the counselee; and (5) services provision. **Sample of validation:** 30 professionals working in genetic counselling field who evaluated 81 consultations. **Reliability estimates:** ranges from .83 to .92.
Satisfaction			
Satisfaction with Genetic Counselling Scale	Shiloh, Avdor, & Goodman (1990)	EBSCO	**Aim:** To measure the satisfaction with the genetic counselling. **Dimensions:** (1) instrumental, (2) affective

(SGCS)			and (3) procedural. **Sample of validation**: 76 counselees of a genetic counselling center. **Reliability estimates:** Not reported.
Genetic Counselling Satisfaction Scale (GCSS)	De Marco, Peshkin, Mars, & Tercyak (2004)	EBSCO	**Aim:** To evaluate whether the board goals of genetic counselling were addressed. **Number of items**: 6. **Sample of validation**: patients seeking prenatal genetic counselling. **Reliability estimates:** .90.
Self-Efficacy			
Genetic Counselling Self-Efficacy Scale (GCSES)	Caldwell, Wusik, He, Yager, & Atzinger (2018)	EBSCO	**Aim:** For (auto) evaluate their professional self-efficacy. **Dimensions:** (1) complex skills; (2) communication; (3) genetic testing; (4) basic psychosocial skills; (5) genetic counselling process; and (6) information gathering. **Sample of validation:** 20 genetic counselling students and 18 genetic counsellors. **Reliability estimates:** .96.

Appendix B. Reciprocal-engagement model of genetic counselling practice

Tenets	Goals	Strategies	Behaviours
Genetics information is Key	Patient is informed Counsellor knows what information to impart Counsellor presents genetics information Patient gains new perspectives	Assess patient educational level Assess patient decision-making style Assess medical literacy Listen for inaccuracy Two-way communication Use visual aids Assess patient understanding	Open and closed questions to gather hx and to determine what patient understands Open and closed questions Ask questions Open and closed questions to determine patient understanding; repeat or rephrase information Explain materials; use language patient can understand Open and closed questions to learn what the information means to the patient
Relationship is integral to genetic counselling	Counsellor and patient establish a bond Good counsellor–patient communication Counsellor characteristics positively influence process	Active listening Behave ethically Recognize impact on session Maintain objectivity Maintain boundaries Self-care Peer supervision	Sit quietly; reflect patient thoughts and feelings; summarize patient statements; rephrase; use similar body language Self-disclose; request feedback; provide feedback
Patient autonomy must be supported	Establish working contract Integrate familial and cultural context into counselling relationship and decisions Patient feels empowered and more in control Facilitate collaborative decisions	Assess patient expectations Provide informed consent Establish realistic agenda Recognize multiple strategies Maintain counselling flexibility Discuss what patient wants to discuss Create safe environment	Ask questions Describe process State goals Reflect patient thoughts and feelings re: options

		Respect patient decision/viewpoint Enable informed actions and decisions Ask about options	
Patients are resilient	Recognize patient strengths Adaptation Empowerment	Identify patient strengths Make connections Anticipatory guidance Instill hope Assimilation Accommodation Create safe environment Maintain/enhance patient self-esteem Identify possible outcomes	Ask questions about patient coping skills
Patient emotions make a difference	Counsellor and patient know pt concerns Patient family dynamics are understood by counsellor and patient. Patient self-esteem is maintained or increased	Recognize ethical dilemmas in patient's life Anticipate patient needs Define patient support network Identify resources Convey empathy	

Note. Adapted from "Coming Full Circle: A Reciprocal-Engagement Model of Genetic Counselling Practice" by P. McCarthy Veach, D. M. Bartels, and B. S. LeRoy, 2007, *Journal of Genetic Counselling, 16*, p. 720 and p. 721.

Appendix C. Cognitive interview probes

Protocol Probes
a. Did you have doubts or hesitate in any question? (Conditional Probe) Please, tell me why you had doubts or hesitated in this (these) question(s)? b. What did you think when you read this (these) question(s)? c. In your words, what do you think that we intend to know with this question? d. Did you think that was easy or difficult to answer this question? e. Why did you choose this answer option? f. What do you think about the scale extension? g. What do you think about the instructions?
Examples of Emergent Probes
a. Is question 3.9. pertinent in your perspective? b. What is that word (or this sentence) means to you?

Appendix D. Scale items: Changes, reasons for change and final wording

Original Wording	Participant(s)	Reason(s) for Change	Final Wording
2.3. O profissional questionou-me acerca dos meus valores e crenças como por exemplo: religião, mitos, projetos de vida relacionados com o aconselhamento genético.	Researcher who had participated in the professionals' scale development	Needed clarification. It is difficult to understand the item. Wording change – "perguntou-me" - was performed to improve the item face validity and its resemblance with the previous item.	O profissional perguntou-me os meus valores e crenças relacionados com o aconselhamento genético, como por exemplo: religião, mitos, projetos de vida.
2.5. Conversamos sobre a forma como os meus antecedentes pessoais e familiares, as minhas redes de apoio social, e a minha forma de lidar com as situações difíceis, se poderão relacionar com as minhas reações emocionais face ao meu diagnóstico.	Researcher P4 P6	Needed clarification. The item is ambiguous. Word change – "neste contexto" - facilitates the comprehension of the item.	Conversamos sobre a forma como os meus antecedentes pessoais e familiares, as minhas redes de apoio social, e a minha forma de lidar com as situações difíceis, se poderão relacionar com as minhas reações emocionais neste contexto.
3.3. A consulta adaptou-se bem às minhas características (por exemplo: valores, preferências, forças e fraquezas).	Researcher	Needed clarification. Wording change - "o professional" - was performed to improve the item face validity and its resemblance with both previous and subsequent items.	O profissional adaptou-se bem às minhas características, como por exemplo: valores, preferências, forças e fraquezas.
3.9. O profissional mostrou ser um especialista credível nesta área o que aumentou a minha	Researcher P5	Needed clarification. It is difficult to understand the item. Wording change - "mostrou estar bem	O profissional mostrou estar bem preparado o que aumentou a minha confiança nele.

confiança nele.		preparado" - was performed to improve the item face validity.	
4.4. A consulta contribuiu para eu lidar melhor com a doença e com o meu risco.	P6	Needed clarification. The item is incomplete. Wording added – "e/ou" – as P6 emphasized some counselees do not have a disease but they are at risk for a disease.	A consulta contribuiu para eu lidar melhor com a doença e/ou com o meu risco.
4.6. A consulta abriu-me novas perspetivas.	Researcher	Needed clarification. It is difficult to understand the item. Wording change – "A deu-me novas formas de ver a minha situação" – to ease the item understanding.	A consulta deu-me novas formas de ver a minha situação.

Appendix E. Reliability analysis of scale dimensions

Item	*N*	Corrected item-total correlations	Cronbach's alpha if item deleted
Counselee's Education α =.70			
1.2.	105	.59	.62
1.3.	105	.57	.63
1.4.	105	.38	.72
1.5.	105	.45	.66
1.12.	105	.57	.62
Counselee's Understanding and Knowledge α =.60			
1.1	105	.18	.61
1.6.	105	.52	.50
1.7.	105	.41	.56
1.8.	105	.31	.58
1.9.	105	.48	.54
1.10.	105	.22	.65
1.11.	105	.47	.50
Counselee's Individual Attributes α =.88			
2.1.	105	.64	.87
2.2.	105	.59	.87
2.4.	105	.55	.87
2.5.	105	.61	.87
2.6.	105	.71	.86
2.7.	105	.75	.86
2.8.	105	.73	.86
2.9.	105	.70	.87
2.10.	105	.44	.88
2.11.	105	.50	.88
Relationship and Communication Issues α =.83			
3.1.	105	.59	.80
3.2.	105	.63	.80
3.3.	105	.44	.82
3.4.	105	.68	.79
3.5.	105	.67	.79
3.6.	105	.54	.81
3.7.	105	.64	.80
3.9	105	.43	.82

Potential Effects α =.90			
4.1.	103	.78	.88
4.2.	103	.64	.89
4.3.	103	.55	.90
4.4.	103	.70	.89
4.5.	103	.70	.89
4.6.	103	.65	.89
4.7.	103	.68	.89
4.8.	103	.75	.88
4.9.	103	.72	.89
4.10.	103	.52	.90
Services Provision α =.73			
5.1.	102	.43	.71
5.2.	102	.46	.70
5.3.	102	.49	.70
5.4.	102	.47	.70
5.6.	102	.52	.71
5.7.	102	.23	.75
5.8.	102	.49	.70
5.9.	102	.48	.70
5.10.	102	.44	.70

Note. Values were calculated using listwise option.

Appendix F. Descriptive statistics for the fifty-two items of the validation version of the scale

Item	*M*	*SD*	*Sk*	*Ku*	% of Missing Values
1.1. Counselee's expectations.	4.28	1.23	-2.08	4.17	.9%
1.2. Information about the disease.	4.52	.98	-2.45	6.36	.9%
1.3. Information about the genetic test.	4.57	.86	-2.66	8.98	.9%
1.4. Information about reproductive alternatives.	3.52	1.99	-.99	-.71	1.9%
1.5. Information about support sources and resources (e.g., patients associations).	3.16	1.80	-.55	-1.1	
1.6. Questions about counselee's understanding.	4.31	1.14	-1.97	3.86	
1.7. Language clarity.	4.64	.76	-3	12.80	
1.8. Doubts.	4.66	.76	-3.09	12.89	
1.9. Information usefulness.	4.52	.90	-2.41	7.03	
1.10. Audiovisual and didactic materials.	2.24	1.98	.24	-1.55	.9%
1.11. Resume information provided.	3.20	1.62	-.50	-.88	
1.12. Confidentially.	4.48	1.13	-2.60	6.71	
2.1. Consultation meeting my needs.	4.55	.85	-2.27	6.81	.9%
2.2. Counselee's reason for consultation.	4.52	1.1	-2.91	8.91	.9%
2.3.Values and beliefs related with genetic counselling (e.g., religion).	2.62	1.97	-.06	-1.61	.9%
2.4. How counselees and their families cope with the disease.	4.07	1.41	-1.51	1.38	.9%
2.5. Counselee's emotional reactions.	4.01	1.45	-1.51	1.28	.9%
2.6. Expression of emotions during the consultation.	4.44	1.01	-2.09	4.58	
2.7. Life changes caused by genetic test.	4.28	1.24	-1.87	3.05	
2.8. Genetic test pros and cons.	4.16	1.35	-1.76	2.50	
2.9. Feeling secure during the consultation.	4.58	.83	-2.47	8.24	
2.10. Informed consent.	4.38	1.29	-2.44	5.40	
2.11. Next steps after the consultation.	4.59	1.06	-3.34	11.56	
3.1. Counselee's acceptance.	4.61	.87	-2.78	9.28	

3.2. Active listening 1.	4.73	.71	-3.78	19.06	
3.3. Counselee-centered consultation.	4.40	1.12	-2.56	7.15	
3.4. Nondirectiveness 1.	3.79	1.68	-1.08	-.31	.9%
3.5. Nondirectiveness 2.	3.83	1.63	-1.22	.07	
3.6. Nondirectiveness 3.	4.22	1.34	-1.83	2.43	
3.7. Counselee-professional communication.	4.67	.81	-3.33	13.39	.9%
3.8. Active listening 2.	4.45	1.12	-2.78	8.08	
3.9. Professional's expertise.	4.72	.82	-4.11	19.66	
4.1. Disease knowledge improvement.	4.44	.97	-1.99	4.39	
4.2. Doubts decrease.	4.33	1.11	-1.88	3.58	.9%
4.3. Empowerment 1.	4.05	1.44	-1.71	2.26	
4.4. Coping with disease and/or risk.	4.04	1.40	-1.64	2.02	
4.5. Empowerment 2.	4.13	1.29	-1.65	2.18	
4.6. New perspectives.	3.84	1.52	-1.30	.76	.9%
4.7. Counselee-professional relationship.	4.34	1.09	-2.09	5.13	
4.8. Expectations meeting.	4.52	.95	-2.31	5.88	.9%
4.9. Satisfaction 1.	4.63	.82	-2.81	9.89	.9%
4.10. Satisfaction 2.	4.60	1	-3.17	11.06	
5.1. Consultation duration.	4.49	.86	-2.03	5.76	
5.2. Consultation preparation 1.	3.09	2.02	-.52	-1.38	.9%
5.3. Consultation preparation 2.	3.10	2.08	-.59	-1.35	1.9%
5.4. Time management 1.	4.07	1.22	-1.42	1.72	
5.5. Audiovisual and didactic materials.	1.96	2.05	.34	-1.61	.9%
5.6. Privacity.	4.72	.72	-3.62	17.27	
5.7. Time management 2.	3.47	2	-.95	-.77	.9%
5.8. Clinical team muldisciplinarity.	4.47	1.11	-2.75	8.09	.9%
5.9. Openness for other family members.	4.25	1.49	-2.22	3.75	.9%
5.10. Openness for future contacts.	4.48	1.23	-2.84	7.56	

Appendix G. Responses distribution for the fifty-two items of the validation version of the scale

	Frequencies (%)					
Item	1	2	3	4	5	NA
1.1. Counselee's expectations.	1.9%	.9%	13.2%	16%	64.2%	3.8%
1.2. Information about the disease.	1.9%	1.9%	8.5%	13.2%	73.6%	.9%
1.3. Information about the genetic test.	.9%		9.4%	16%	72.6%	.9%
1.4. Information about reproductive alternatives.	2.9%	1%	10.5%	12.4%	53.3%	20%
1.5. Information about support sources and resources (e.g., patients associations).	10.3%	10.3%	14%	18.7%	33.6%	13.1%
1.6. Questions about counselee's understanding.	2.8%	1.9%	12.1%	18.7%	62.6%	1.9%
1.7. Language clarity.			7.5%	16.8%	74.8%	.9%
1.8. Doubts.			8.4%	12.1%	78.5%	.9%
1.9. Information usefulness.	.9%	.9%	10.3%	15.9%	71%	.9%
1.10. Audiovisual and didactic materials.	18.9%	6.6%	12.3%	10.4%	22.6%	29.2%
1.11. Resume information provided.	13.1%	7.5%	27.1%	14%	30.8%	7.5%
1.12. Confidentially.	1.9%	.9%	8.4%	11.2%	74.8%	2.8%
2.1. Consultation meeting my needs.			14.2%	12.3%	72.6%	.9%
2.2. Counselee's reason for consultation.			9.4%	10.4%	76.4%	3.8%
2.3. Values and beliefs related with genetic counselling (e.g., religion).	20.8%	2.8%	16%	10.4%	29.2%	20.8%
2.4. How counselees and their families cope with the disease.	5.7%	2.8%	15.1%	13.2%	59.4%	3.8%
2.5. Counselee's emotional reactions.	5.7%	3.8%	11.3%	18.9%	55.7%	4.7%
2.6. Expression of emotions during the consultation.	1.9%	1.9%	12.1%	14%	69.2%	.9%
2.7. Life changes caused by genetic test.	1.9%	4.7%	12.1%	12.1%	66.4%	2.8%
2.8. Genetic test pros and cons.	1.9%	3.7%	14%	14%	61.7%	4.7%
2.9.Feeling secure during the consultation.			12.1%	13.1%	73.8%	.9%
2.10. Informed consent.		1.9%	8.4%	11.2%	72.9%	5.6%

2.11. Next steps after the consultation.			5.6%	11.2%	79.4%	3.7%
3.1. Counselee's acceptance.	.9%		10.3%	10.3%	77.6%	.9%
3.2. Active listening 1.			5.6%	11.2%	82.2%	.9%
3.3. Counselee-centered consultation.		.9%	9.3%	19.6%	66.4%	3.7%
3.4. Nondirectiveness 1.	12.3%	3.8%	11.3%	9.4%	57.5%	5.7%
3.5. Nondirectiveness 2.	12.1%	.9%	10.3%	16.8%	54.2%	5.6%
3.6. Nondirectiveness 3.	6.5%	.9%	10.3%	14%	65.4%	2.8%
3.7.Counselee-professional communication.	.9%		6.6%	11.3%	80.2%	.9%
3.8. Active listening 2.	.9%		6.5%	19.6%	69.2%	3.7%
3.9. Professional's expertise.			4.7%	9.3%	84.1%	1.9%
4.1. Disease knowledge improvement.	.9%	1.9%	14%	14%	68.2%	.9%
4.2. Doubts decrease.	.9%	3.8%	14.2%	14.2%	65.1%	1.9%
4.3. Empowerment 1.	.9%	.9%	17.8%	15.9%	57%	7.5%
4.4. Coping with disease and/or risk.	2.8%	2.8%	14%	20.6%	54.2%	5.6%
4.5. Empowerment 2.	4.7%	1.9%	15%	18.7%	57%	2.8%
4.6. New perspectives.	5.7%	.9%	20.8%	16%	50%	6.6%
4.7. Counselee-professional relationship.		.9%	16.8%	15.9%	63.6%	2.8%
4.8. Expectations meeting.	.9%	1.9%	11.3%	11.3%	73.6%	.9%
4.9. Satisfaction 1.		.9%	9.4%	10.4%	78.3%	.9%
4.10. Satisfaction 2.			9.3%	7.5%	80.4%	2.8%
5.1. Consultation duration.			15%	16.8%	67.3%	.9%
5.2. Consultation preparation 1.	9.4%	2.8%	15.1%	10.4%	41.5%	20.8%
5.3. Consultation preparation 2.	3.8%	1%	15.2%	12.4%	41.9%	25.7%
5.4. Time management 1.	4.7%	.9%	21.5%	19.6%	51.4%	1.9%
5.5. Audiovisual and didactic materials.	7.5%	1.9%	14.2%	13.2%	17.9%	45.3%
5.6. Privacity.			6.5%	10.3%	82.2%	.9%
5.7. Time management 2.		2.8%	12.3%	11.3%	51.9%	21.7%
5.8. Clinical team muldisciplinarity.			10.4%	13.2%	72.6%	3.8%
5.9. Openness for other family members.			5.7%	16%	68.9%	9.4%
5.10. Openness for future contacts.			6.5%	11.2%	76.6%	5.6%

Note. Presented percentages are valid percentages.

Proposal of a Portuguese Scale for Quality Assessment of Genetic Counselling by Counselees

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